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ABSTRACT

The document--one third of which consists of appendixes--presents the final report of a 3 year national study to evaluate the quality and quantity of minority participation in the developmental disabilities (DD) movement, in such areas as service recipients, planning, policy formation, administration, and decision making. Study objectives were to determine the structure and demographic characteristics of DD agencies, the extent and nature of services provided by the agencies, the characteristics of the clientele, the extent and level of participation, and the unmet needs of minority DD people. The study was divided into three parts: a series of nationwide meetings with consumers and agencies to obtain comments and recommendations to be used in developing the survey instrument, a literature review to provide additional background on trends in the movement, and a national survey of 1,200 agencies. The final report covers the history of the investigation, the literature review, major findings, methodology, data analysis, discussion of key findings, and recommendations and suggested action plans. A selected bibliography is included. Among the eight appendixes are questionnaires and a list of project resources. (DLS)

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THE DEVELOPMENTAL DISABILITIES MOVEMENT: A NATIONAL STUDY OF MINORITY PARTICIPATION

This is the final report of the study: A Nationwide Study to Identify and Evaluate the Quality and Quantity of Minority Participation in the Developmental Disabilities Movement. This study was funded under Grant #54-P-71193/9-02 by the Office of Human Development Services, Bureau of Developmental Disabilities, U.S. Department of Health, Education, and Welfare. This report does not, however, reflect the policies or opinions of the Department of Health, Education, and Welfare.

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November 1979

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FOREWORD

We in the developmental disabilities field recognize the responsibility of identifying and serving all those in need of our services. While all developmentally disabled persons are special and have problems in accessing services and in finding agencies/organizations who are sensitive to their needs, developmentally disabled persons who are members of racial/ethnic groups seem to be particularly isolated from the mainstream of the developmental disabilities service system, and seem to have greater problems in locating and accessing services.

Past observations indicate a lack of minority involvement in the planning, and policy development, and further, a gap in information upon which to assess this lack of involvement.

It was because of this that the Developmental Disabilities Office awarded a grant to New Dimensions in Community Service, Inc. to conduct a nationwide study on minority participation in the developmental disabilities movement.

This final report is a result of the work performed under that grant. It is the hope of this office that the report will provide service providers (agencies and organizations) with new and effective ideas and ways to involve the minority developmentally disabled consumer; that it will foster renewed commitment to treat each consumer and his needs on an individual basis, recognizing and being sensitive to the differences caused by language patterns, cultural beliefs, life-styles and family and community structures, while never losing sight of the similarities among those in need.

Further, we believe that as the developmental disabilities movement develops ways to better engage the minority developmentally disabled consumer, a ripple effect will occur and the involvement of all developmentally disabled consumers will be enhanced.

The DDO joins with those in the DD movement to work towards planning and implementing services for the disabled. But this planning cannot be done in isolation from those who will be affected. We cannot plan for. Rather, we must plan with. Together we can do more to serve those who are in need.

We commend the agencies who voluntarily participated in the survey, the parents of the DD, and concerned individuals who gave freely of their ideas. And we thank New Dimensions in Community Service, Inc., and the project staff for its diligence in implementing the study.

Francis X. Lynch
Director
Bureau of Developmental Disabilities

ACKNOWLEDGEMENTS

This study was made possible by a grant from the Office of Human Development Services, Developmental Disabilities Office, Department of Health, Education, and Welfare, and the support, cooperation and input from many individuals, groups, and organizations throughout the country. In addition to the hard work and dedication of the project staff and consultants, we wish to salute all those who helped make this report a reality by contributing advice, information, recommendations, and other assistance to the successful completion of the study on which this report is based.

We at New Dimensions in Community Service, Inc. (NDCS) would like to give special recognition to the Bureau of Developmental Disabilities, Office of Human Development Services, Department of Health, Education, and Welfare (DHEW), which made the study possible. We wish to express special thanks and appreciation to our Project Monitor, Mrs. Thelma Lucas, Program Specialist, Office of Research, Rehabilitation Services Administration, DHEW, for her guidance and consistent support, and to Francis X. Lynch, Director, Bureau of Developmental Disabilities and Mrs. Doris Haar of the Division of Developmental Disabilities for their cooperation and assistance.

We also wish to recognize the contributions of the many national and local private and governmental groups and agencies. Among other assistance, they provided the names of organizations and individuals to participate in the nationwide meetings with parents, consumers, and service providers held during the first phase of the study.

These groups include the following:

- United Cerebral Palsy Association
- Epilepsy Foundation of America
- Affiliates of the National Urban League
- Associations for Retarded Citizens
- State Developmental Disability Councils

- Department of Health in Hawaii and Nebraska
- Department of Human Resources in Nevada and Oregon
- Department of Mental Health in Indiana, Mississippi, and Missouri
- State Departments of Mental Retardation
- Department of Social and Rehabilitation Services, Kansas
- Department of Health and Rehabilitation Services, Florida
- Department of Economic Security, Arizona
- Association for the Disabled of Elkhart County, Indiana
- American Academy of Pediatrics, Illinois
- Regional Offices of Developmental Disabilities
- Bureau of Developmental Disability Services, New York
- Community Development Program, Chicago
- William L. Dawson Day Care Center, Chicago
- Social Services Agency, New Mexico
- Children's Hospital of Arizona
- Oklahoma Children's Hospital
- United Planning Organization, Washington, D.C.
- North Central District Health Department, Idaho
- Yavapai Rehabilitation Center, Arizona
- South Dakota United Indian Association (Wiconi Project)
- Council of Community Services, Tennessee
- Project Head Start, South Dakota
- North Central Pennsylvania Community Mental Health/ Mental Retardation Center
- White House Conference on Handicapped Individuals, Washington, D.C.
- the President's Committee on Mental Retardation, Washington, D.C.
- American Society for Allied Health Professionals, Washington, D.C.

Additionally, we wish to express appreciation and gratitude to the many people who assisted with the logistics for the nationwide meetings, or provided meeting facilities. Also, we wish to recognize the developmentally disabled consumers, their parents and guardians, the professionals and organizations, and other concerned individuals who participated in the nationwide meetings. These participants contributed invaluably through their input on service needs and their suggestions, which were useful in guiding the development of the survey instrument.

NDCS is also appreciative of the Panel of Judges who reviewed and critiqued the survey instrument. And we wish to thank, too, the many federal governmental agencies who provided essential information which helped to identify information sources on the minority developmentally

disabled. These included the following agencies:

- Center for Minority Group Mental Health of the National Institute of Mental Health
- the United States Census Bureau
- the United States Civil Rights Commission
- Rehabilitation Services Administration, DHEW
- Office of Child Development, DHEW
- Office of Human Development Services, DHEW
- Office of Research and Statistics, DHEW
- Social Security Administration, DHEW

Without the participation of the more than 800 agencies who responded to the questionnaire, this report would not be possible, and we wish to express our gratitude to them, too.

Finally, we wish to express special thanks to the project staff and consultants who worked diligently to research the latest state-of-the-art of minority participation in developmental disability programs. They contributed both to the study and to the preparation of the final report. This team consisted of:

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GLOSSARY OF TERMS

Essential to understanding the study are the definitions of basic terms used in the report. The terms for racial/ethnic minorities are based on the Office of Management and Budget's "Race and Ethnic Standards for Federal Statistics and Administrative Reporting," (Circular No. A-46, Revised. 1977).

MINORITY/NON-MINORITY

Minority includes Asian, Black, Native American Indians, and Spanish-speaking surname persons. Specific designations for each population are as follows:

American Indian or Alaskan Native: A person having origins in any of the original peoples of North America, and who maintains cultural identification through tribal affiliation or community recognition.

Asian or Pacific Islander: A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, Japan, Korea, Philippine Islands, and Samoa.

Black (not of Hispanic Origin): A person having origins in any of the racial groups of Africa.

Hispanic: A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.

White (not of Hispanic Origin): A person having origins in any of the original peoples of Europe, North Africa or the Middle East.

DEVELOPMENTAL DISABILITIES (DD)

A developmental disability is defined in Public Law 95-602, as amended in 1978. This definition reads as follows:

> "The term 'developmental disability' means a severe, chronic disability of a person which—
>
> "(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> "(B) is manifested before the person attains age twenty-two;
>
> "(C) is likely to continue indefinitely;
>
> "(D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and

"(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

Other Key terms and their definitions are as follows:

Minority Participation: This is the involvement by minorities as staff, consumers of services, and/or as members of boards, committees, or interested individuals having input into the developmental disability service system.

DD Movement: This movement includes those agencies, groups, or organizations which provide DD services or support the provision of such services.

STAFF

Administrative Staff: Persons who set broad policies, exercise overall responsibility for the execution of these policies, or direct individual departments or special phases of the agency/organization's operations. These staffers include executive directors, program and fiscal managers, planners, supervisors, persons handling staff development or in-service training programs, and others acting in a similar capacity.

Direct Service Staff: Professional or para-professionals who work directly (or in a support capacity) with DD persons and their families. These include: Social workers, counselors, house parents, medical or paramedical workers, and other acting in a similar capacity.

Outreach Staff: Persons responsible for community organization and education (i.e., interpreting agency programs and services), and for identifying potential clients and community resources.

Clerical Staff: Persons responsible for internal and external communications, recording, and other paper-work required in an office. These include clerks, receptionists, secretaries, and others acting in a similar capacity.

Volunteer Staff: Persons who provide a non-paid service and work with paid staff towards organization objectives.

SERVICE

Service refers to the direct or indirect provision of assistance or the transfer of information or materials by public agencies, groups, or organizations to developmentally disabled persons and their families.

As defined by Public Laws 94-103 and 94-602, such activities include:

Identification: diagnosis, evaluation, providing information and referral

Direct Services:	counseling, planning and coordinating services; offering social, sociological, and legal services; assistance at court; and follow-along aid
Treatment:	medical, dental, and occupational therapy, or other special treatment
Education:	pre-school, school-age, adult, day care, health education, and other types of education or training
Residential Services:	domiciliary care, special living arrangements
Employment:	job placement, training, work in a sheltered environment, etc.
Family/Program Support:	recreation, personal care, and transportation

REGIONS

The Department of Health, Education and Welfare divides the 51 states and territories into ten geographic areas for programmatic and administrative purposes. The ten regions consist of the following states and territories:

Region I:	Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont
Region II:	New York, New Jersey, Puerto Rico, and the Virgin Islands
Region III:	Delaware, Maryland, Pennsylvania, Virginia, West Virginia, and the District of Columbia
Region IV:	Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee
Region V:	Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin
Region VI:	Arkansas, Louisiana, New Mexico, Oklahoma, Texas
Region VII:	Iowa, Kansas, Missouri, Nebraska
Region VIII:	Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming
Region IX:	Arizona, California, Hawaii, Nevada, Guam and the Trust Territory of the Pacific Islands
Region X:	Alaska, Idaho, Oregon, Washington

DEPARTMENT OF HEALTH, EDUCATION AND WELFARE
REGIONAL BOUNDARIES
TEN REGIONS

LEGISLATION AFFECTING DD SERVICES

Public Law 94-103: Developmentally Disabled Assistance and Bill of Rights Act of 1975

Public Law 95-602: Amendment to P.L. 94-103, 1978

I: INTRODUCTION

The developmental disabilities movement is a growing part of American life. On the one hand, families with developmentally disabled[1] members have been increasingly demanding more appropriate services, and on the other hand, funding sources are seeking increased information about the services needed and received by the developmentally disabled. At the same time, attitudes towards the developmentally disabled have been changing, and society has been coming to recognize that such persons have as much right as other citizens to acquire an education and job skills, and to lead as normal a life as possible.

Reflecting this expanding concern, the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103) was passed in 1975 to provide specialized services for disabled persons.

The Federal government first began to take a comprehensive approach to funding programs for the developmentally disabled in 1970 with the enactment of P.L. 91-517. Before then, federal support was targeted to one disability, mental retardation, which was provided for by the Mental Retardation Facilities and Community Health Centers Construction Act of 1963. P.L. 91-517 was subsequently amended by P.L. 94-103 in 1975, and further amended by P.L. 95-602 in 1978.

---

[1] For our purposes, "developmentally disabled" is defined as in the Developmentally Disabled Assistance and Bill of Rights Act to be those disabilities which originate in childhood and are attributable to mental retardation, cerebral palsy, epilepsy, autism, specific learning disabilities or to certain other neurological conditions. Such disabilities continue indefinitely and constitute a severe handicap with respect to one's ability to function adequately for personal or social needs.

These pieces of legislation provide the most direct and identifiable federal funds for the disabled. All other funds are provided through legislation and departments whose service population may include the disabled, but which do not serve the latter as a target group. Some of the federal departments or programs which include services to the disabled along with other groups are:

- Social Security Disability Insurance (SSDI)
- Aid to Families with Dependent Children (AFDC)
- Social and Rehabilitative Services
- Crippled Children's Services
- Health Services and Mental Health Administration
- Maternal and Child Health Service
- Maternal and Infant Care
- Community Mental Health Centers
- Bureau of Education for the Handicapped
- Social Security Administration
- Rehabilitation Services Administration
- Bureau of Indian Affairs
- Office for Civil Rights

The major enabling legislation providing services for these and other groups include the Social Security Act (particularly Titles V, XX, and XIX), the Education for All Handicapped Children's Act, the Elementary and Secondary Education Act, the Rehabilitation Act, the Public Health Service Act, and the Civil Rights Act.[2] P.L. 95-602, as noted, is the only act that provides funds directly targeted for the disabled.

It is estimated that the allocations under the above legislation total in the billions of dollars. However, since the allocations are not linked to specific groups served, there is no way to tell how much is spent on a specific disability, except in the case of P.L. 94-103 and P.L. 95-602.

---

[2]For greater detail and discussion of Federal Resources see Guide to Federal Resources for the Developmentally Disabled. Federal Programs Information and Assistance Project, Washington, D.C. December, 1977.

During the fiscal years 1978/79, the funds allocated under these acts were distributed as follows:

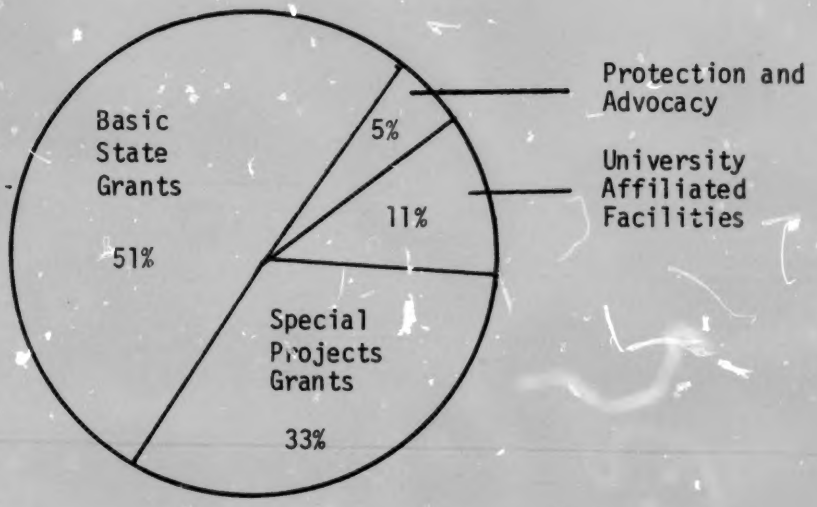


Figure 1: Fiscal Year 1978 Allocation of DD Funds - P.L. 94-103
Total: $59,125,000

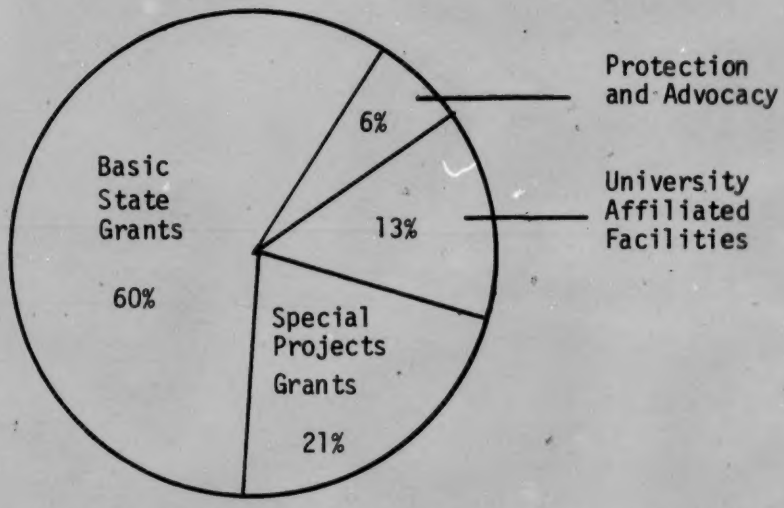


Figure 2: Fiscal Year 1979 Allocation of DD Funds - P.L. 95-602
Total: $59,125,000

Source: Office of Human Development Services, Rehabilitation Services Administration

Although the total allocation, $59,125,000 was the same each year, the Basic State Grants, which provide support to states when they serve the disabled, increased from 51% of the total allocated in 1978 to 60% in 1979. Concurrently, the University Affiliated Facilities (UAF), which act as demonstration centers in providing both services for the disabled and interdisciplinary training programs for personnel serving the latter, received a slight increase in funds. Also receiving a slight increase in funds were the Protection and Advocacy (P & A) Systems. These systems, which are independent of any state agency serving the disabled, advocate and protect the rights of such individuals through their authority to pursue legal, administrative, and other appropriate remedies for those receiving treatment or rehabilitation services within the state.[3]

On the other hand, Special Projects Grants received a decrease in funding. These provide funds for various purposes, which include funds for DD programs, studies, services, etc., to expand public awareness, better coordinate existing resources, provide technical assistance for services, demonstrate or develop new ways of service delivery, gather and disseminate information, improve the quality of services provided, and improve the administration of programs.

Because these funds are distributed on a matching basis, the actual allocation represents only a portion of what is spent. Usually, the matching is on a 75/25 basis (except for programs in rural or urban poverty areas, where the match is 90/10). Thus, normally, for every

---

[3]For an indepth discussion on Protection and Advocacy Systems, see Susan Weisberg, Statewide Advocacy Systems for the DD: Profiles in Innovation, ABA Commission on the Mentally Disabled, Washington, D.C., December, 1978.

three dollars of federal funds spent, one dollar must come from the community. Because of this arrangement, the $59 million in federal funds directed to the disabled generated $78 million or more in DD directed programs, goods, and services.

Broken down on a state by state basis, these $59 million in funds are allocated to each region as follows, based on the size of the states in the region, the working population, and the extent of financial need:

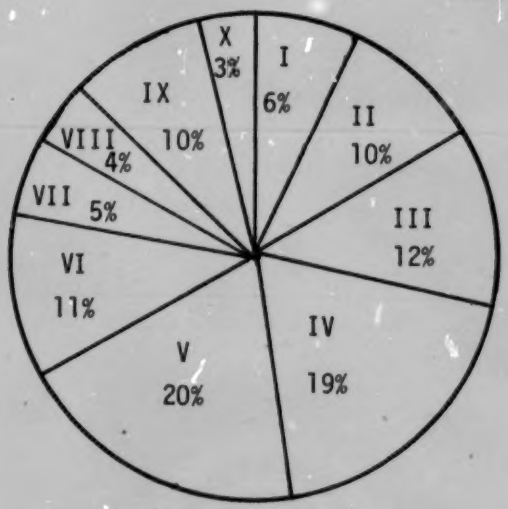


Figure 3: Percentage of Grants by Region, 1978.

FY '78	
Basic State Grants =	$29,144,459
Protection and Advocacy =	$ 2,852,780
Total =	$31,997,239

Source: Office of Human Development Services, Rehabilitation Services Administration, DHEW

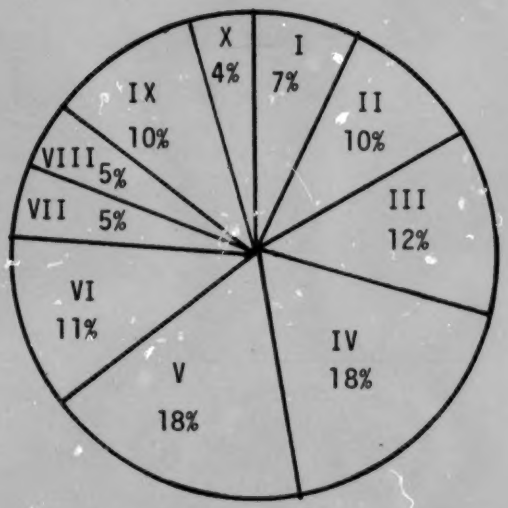


Figure 4: Percentage of Grants by Region, 1979.

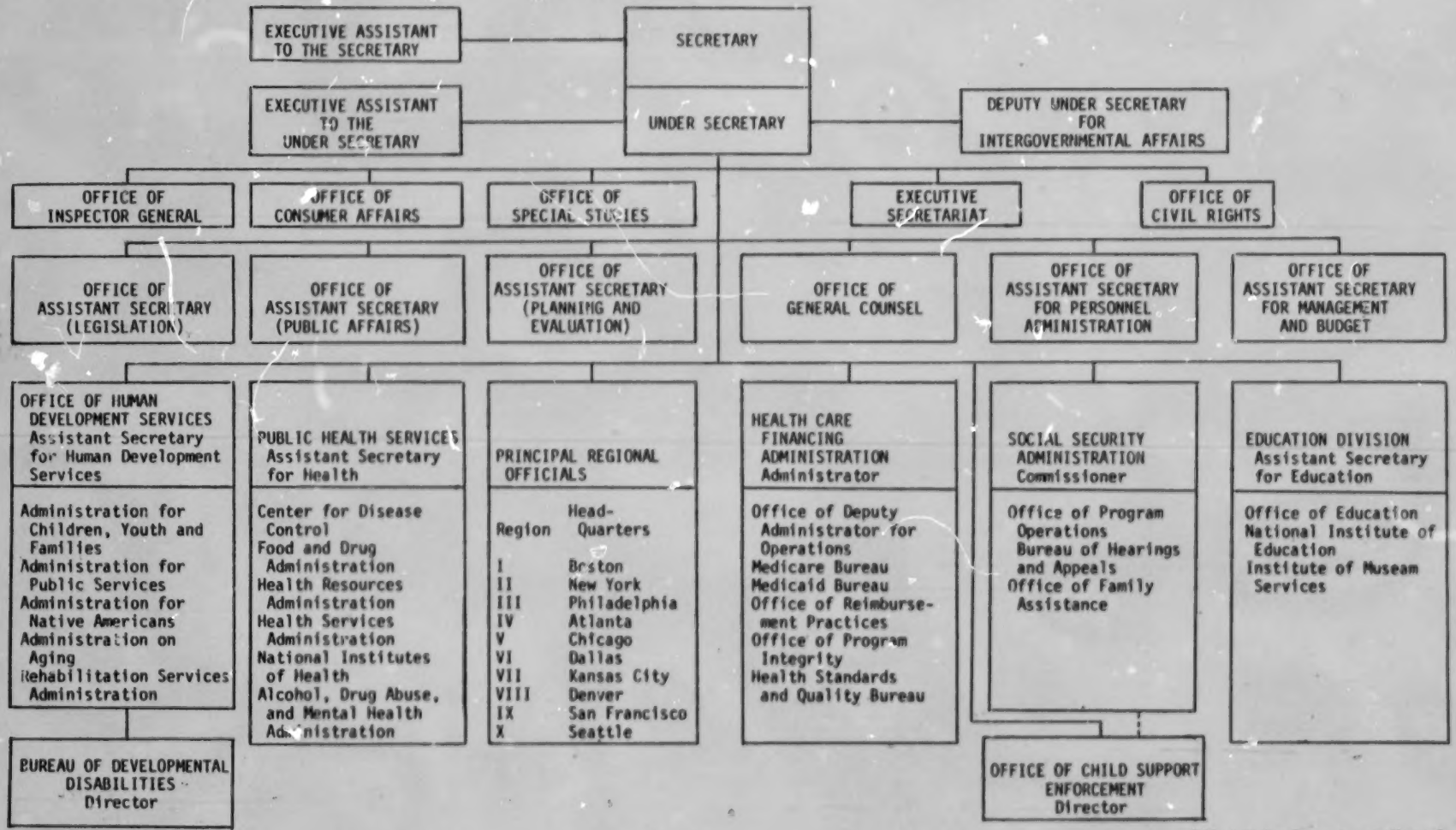
FY '79	
Basic State Grants =	$34,237,931
Protection and Advocacy =	$ 3,668,782
	$37,906,713

These funds allocated under P.L. 95-602 are administered by the Rehabilitation Services Administration, Bureau of Developmental Disabilities, in HEW's Office of Human Development Services. The location of this Administration in HEW is shown on chart I.

This growing involvement of the government has in turn generated increased interest in the nature and extent of the services currently being provided to the disabled, and has raised the question of whether the agencies serving them are adequately meeting their needs, and particularly the needs of affected minorities.

Participation by affected minority families in service planning is restricted by a number of factors, including limited knowledge about developmental disabilities and attitudinal constraints. Among those conditions classified as developmental disabilities, mental retardation is usually the only handicap of which minority populations have any understanding, and that

CHART 1: ORGANIZATIONAL CHART: DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE


EXECUTIVE ASSISTANT TO THE SECRETARY
SECRETARY
EXECUTIVE ASSISTANT TO THE UNDER SECRETARY
UNDER SECRETARY
DEPUTY UNDER SECRETARY FOR INTERGOVERNMENTAL AFFAIRS
OFFICE OF INSPECTOR GENERAL
OFFICE OF CONSUMER AFFAIRS
OFFICE OF SPECIAL STUDIES
EXECUTIVE SECRETARIAT
OFFICE OF CIVIL RIGHTS
OFFICE OF ASSISTANT SECRETARY (LEGISLATION)
OFFICE OF ASSISTANT SECRETARY (PUBLIC AFFAIRS)
OFFICE OF ASSISTANT SECRETARY (PLANNING AND EVALUATION)
OFFICE OF GENERAL COUNSEL
OFFICE OF ASSISTANT SECRETARY FOR PERSONNEL ADMINISTRATION
OFFICE OF ASSISTANT SECRETARY FOR MANAGEMENT AND BUDGET
OFFICE OF HUMAN DEVELOPMENT SERVICES Assistant Secretary for Human Development Services
Administration for Children, Youth and Families
Administration for Public Services
Administration for Native Americans
Administration on Aging
Rehabilitation Services Administration
BUREAU OF DEVELOPMENTAL DISABILITIES Director
PUBLIC HEALTH SERVICES Assistant Secretary for Health
Center for Disease Control
Food and Drug Administration
Health Resources Administration
Health Services Administration
National Institutes of Health
Alcohol, Drug Abuse, and Mental Health Administration
PRINCIPAL REGIONAL OFFICIALS
Region Head-Quarters
I Boston
II New York
III Philadelphia
IV Atlanta
V Chicago
VI Dallas
VII Kansas City
VIII Denver
IX San Francisco
X Seattle
HEALTH CARE FINANCING ADMINISTRATION Administrator
Office of Deputy Administrator for Operations
Medicare Bureau
Medicaid Bureau
Office of Reimbursement Practices
Office of Program Integrity
Health Standards and Quality Bureau
SOCIAL SECURITY ADMINISTRATION Commissioner
Office of Program Operations
Bureau of Hearings and Appeals
Office of Family Assistance
OFFICE OF CHILD SUPPORT ENFORCEMENT Director
EDUCATION DIVISION Assistant Secretary for Education
Office of Education
National Institute of Education
Institute of Museum Services

understanding is general. It is also negative, in part because of the "labeling" effect by educators, in part because of the feeling many minority families share that children may have been deprived of care at an early age when some disabilities are treatable.

In a project funded by the California State Health Department in 1976 to educate Black communities on developmental disabilities, New Dimensions in Community Service, Inc., found that most Blacks and other minorities use medical assistance largely on a crisis basis, with the result that many disabling disabilities such as mild retardation or epilepsy are not being diagnosed in early childhood.

There are also economic barriers to minority participation. With traditional high levels of unemployment and low wages, minority families struggling to afford such basic necessities as food and shelter find little time to devote to the arduous process of planning and implementing social programs. Accessibility is another problem. Rural Indian populations, for instance, may not have access to services, and service groups may not be providing outreach programs to learn of and satisfy their needs. Strong cultural traditions and neighborhood identities can also deter minorities from locating, utilizing, and helping to improve existing institutional or centralized services.

Given these additional obstacles, it is essential that service agencies make a special effort to recruit minorities into the planning and decision making processes. Currently there is no data on where and how this effort is being made, if at all.

There is growing recognition that understanding, participation, and supportive services in minority communities must be improved. The Developmental Disabilities Office of the Office of Human Development Services,

Department of Health, Education, and Welfare is administering and funding service and research programs. The California State Health Department is beginning to include minority programs as an objective and provide funding to plan systematic delivery of such needed and related services as day care, transportation, training and employment programs.

To a great extent, the growing interest among the handicapped in the rights and concerns of the disabled has been modeled after the Civil Rights movement of the 1960's, when Black groups first organized systematic efforts to gain entry into levels of society previously closed to them.

Many observers and participants have compared the emerging struggle of the disabled to this earlier rights movement. Some have pointed out that the struggle of the minority disabled is especially difficult since they have both physical and racial barriers to overcome. The latter is likely to have a greater need for service, but more difficulty in gaining access to this service, or participating in related decision-making.

A study to determine actual and perceived minority representation was considered the first step toward removing barriers to minority participation, prevention, and early detection, and toward transformation of inequitable and inadequate services.

Accordingly, this three-year study was begun in 1976 under the auspices of the Developmental Disabilities Office (now the Bureau of Developmental Disabilities), which is part of HEW, to assess the level of minority participation in the developmental disabilities movement and the barriers to such participation.

The study was directed towards the following goal and major objectives:

Goal: To identify and evaluate the quality and quantity of minority participation in the developmental disabilities movement.

Objectives: To conduct a nationwide fact-finding study to determine:

A. Structure and demographic characteristics of DD agencies

B. Extent and nature of services provided by agencies

C. Characteristics of clientele

D. Extent and level of participation

E. Unmet needs of minority developmentally disabled*

While not measurable within the scope of this study, it is our hope that the results of the study will bring increased attention to prevention and early detection, increased advocacy for the minority developmentally disabled, and increased service and support for their families.

To achieve these objectives, the study was divided into three parts--a series of nationwide meetings with consumers and agencies to obtain comments and recommendations to be used in developing the survey instrument; a literature review to provide additional background on trends in the movement; and a nationwide survey of 1,200** agencies using the questionnaire developed by the project (for a diagrammatic representation of the research process, see chart 2).

More specifically, the purposes and activities of these three phases were as follows:

* Only the perceptions of unmet needs based on the survey are those of service providers. Although the original purposal called for a survey of parents/consumers, it was not possible to implement as part of this study. Thus, the only consumer input came from nationwide meetings.

**Our desired sample size was set at 1,200 (the reasons for this choice are given in Appendix E). In anticipation on non-responding by agencies, we followed standard practice and oversampled by 25%, thus sending questionnaires to 1,500 agencies.

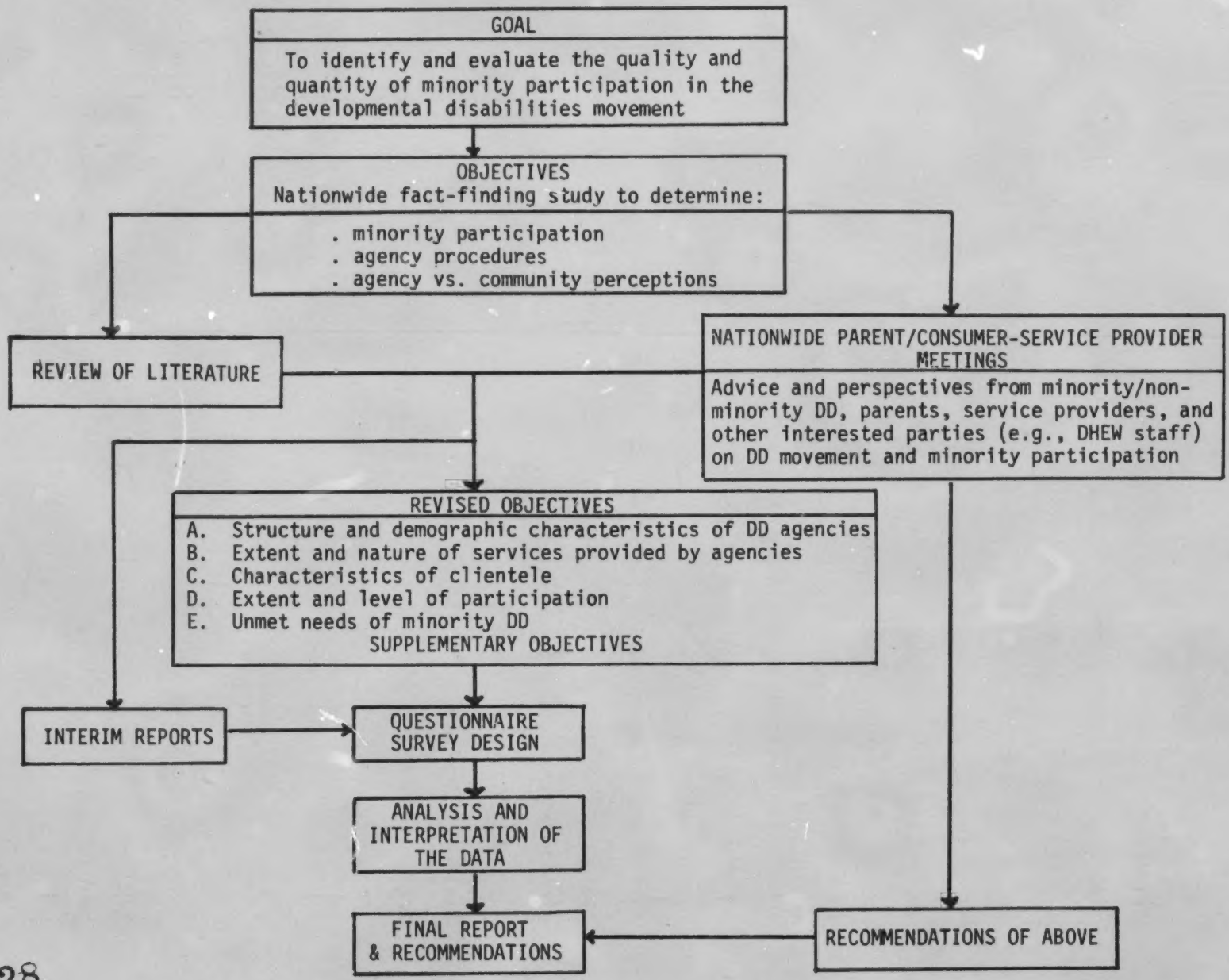

GOAL
To identify and evaluate the quality and quantity of minority participation in the developmental disabilities movement
OBJECTIVES
Nationwide fact-finding study to determine:
. minority participation
. agency procedures
. agency vs. community perceptions
REVIEW OF LITERATURE
NATIONWIDE PARENT/CONSUMER-SERVICE PROVIDER MEETINGS
Advice and perspectives from minority/non-minority DD, parents, service providers, and other interested parties (e.g., DHEW staff) on DD movement and minority participation
REVISED OBJECTIVES
A. Structure and demographic characteristics of DD agencies
B. Extent and nature of services provided by agencies
C. Characteristics of clientele
D. Extent and level of participation
E. Unmet needs of minority DD
SUPPLEMENTARY OBJECTIVES
INTERIM REPORTS
QUESTIONNAIRE SURVEY DESIGN
ANALYSIS AND INTERPRETATION OF THE DATA
FINAL REPORT & RECOMMENDATIONS
RECOMMENDATIONS OF ABOVE

Chart 2: Diagrammatic Representation of the Research Process

The Nationwide Meetings

A series of nationwide meetings were held in 14 major U.S. cities primarily to obtain the advice of disabled persons (the majority of whom were minority individuals), parents of disabled children or other advocates of the disabled, and service provider representatives. The selection of cities was based on 1970 census data on the geographic location of large numbers of minority population, the availability of adequate facilities for holding the meetings, the accessibility of the meeting place to the handicapped, and air and surface transportation.

The purpose of the meetings was to elicit comments from parents, consumers and service providers and answer and/or clarify any questions they had about the study. The agenda items were used for discussion purposes with parents/consumers and service providers, thus allowing us to compare differences and discrepancies in perception of service needs and participation. (See Apendix G.) The parents/consumers met in A.M. sessions and service providers in P.M. sessions.

The selection process involved primarily the identification of national, state and local organizations working with minority groups and/or serving the developmentally disabled, such as: DD Councils, President's Committee on Mental Retardation, National Association for Retarded Citizens, Head Start programs, HEW Regional Offices of DD, National Urban League, Aspira, S.D. United Indian Association, Indian Health Service, Yavapai Rehabilitation Center, etc. They were asked to submit names of parents/consumers to invite to the meetings. The high response rate of consumer participation (approximately 500) was partially due to the availability of travel and per diem stipends. The majority of participants, however, resided in areas close to the location of the meetings. (See Appendix G for samples of letters.)

The Literature Review

This review was designed to provide a broad background on the patterns of service and previous research findings on the movement to supplement and expand upon the information derived from the nationwide meetings. It was expected that this review would provide additional insights to assist the project in designing the survey instrument.

The literature to be reviewed was identified with the assistance of the Council for Exceptional Children, the computer facilities at the library of the University of California at Berkeley, and the Center for the Study of Minority Group Mental Health of the National Institute of Mental Health.

The results of this literature review are described in Section III of this report.

The Survey

The survey was designed to obtain quantifiable data on the nature and extent of minority participation in the DD movement and on the DD movement generally. In particular, the data sought included the following areas of information:

- Structure and demographic characteristics of DD agencies
- Extent and nature of services provided by agencies
- Characteristics of clientele
- Extent and level of participation
- Unmet needs of minority developmentally disabled

This information was obtained from a variety of agencies including hospitals, sheltered workshops, Departments of Rehabilitation, associations for the retarded, day care centers, etc. The agencies surveyed were selected through sampling procedures that are fully described in Appendix E of the report, while survey findings are separately analyzed and presented later in this report.

It would be most desirable to obtain information about the quality and nature of DD services offered from both service providers and consumers since they can have very different views on the service provided. However, due to practical considerations, described elsewhere in the report, most of the data was obtained from service providers. It is hoped that in the near future, systematic studies will be done to assess the viewpoints of service consumers on similar issues contained in our survey instrument.

II. HISTORY OF THE INVESTIGATION

Authorization

In 1976, the Developmental Disabilities Office, Office of Human Development Services, Department of Health Education, and Welfare, disseminated a request for proposal (RFP) for the purpose of implementing a nationwide study to identify and evaluate the quantity and quality of minority participation in the developmental disabilities (DD) movement.

In its RFP, the Developmental Disabilities Office noted a lack of information concerning the quantity and quality of minority input into planning, policy development, and implementation strategies. Respondents to the RFP were encouraged to utilize methods to involve the target populations in shaping the strategies for change as well as representatives of the existing system.

New Dimensions in Community Service, Inc., a human service organization based in San Francisco, responded to the RFP and was awarded the grant in October, 1976.

In its response to the RFP, New Dimensions formulated its goal and objectives, as follows:

Goal: To identify and evaluate the quality and quantity of minority participation in the developmental disabilities movement.

Objectives:

1. To conduct a nationwide fact-finding study on the numbers of minorities participating in planning and implementation of DD services.
    a. To identify agency procedures for recruiting minority ideas and receiving input on service needs.
    b. To compile recommendations for change.
2. To assess the level of minority participation.
    a. To compare agency and community perceptions of minority involvement and needs.

b. To assess strategies for increasing minority participation and making it more effective.

3. To make resource and study information available to agencies and communities.

4. To recommend a plan-of-action for State DD Planning Councils and other policy and planning bodies to increase effective minority participation in their decisions.

There is a myriad of state and local agencies, programs and legislation whose objectives are to identify and serve various portions of the developmentally disabled population. Added to this are the various planning, consumer advocacy and professional and consumer organizations who seek to improve services and ensure consumer/client and professional input into decision-making. Among these are the National Association for Retarded Citizens, the Epilepsy Foundation of America, the National Society for Autistic Children, the Council for Exceptional Children, United Cerebral Palsy Associations, the American Association on Mental Deficiency, and Protection and Advocacy Units. These groups join with the state and local agencies and programs to form what is euphemistically referred to as the "DD Movement."

The present study sought to examine minority participation in that movement, and to find answers to questions relating to the lack of minority participation in the movement. For example: What are the barriers to participation? What role does agency size (budget), location, outreach efforts, or staff composition play in participation by minority consumers?

The impetus for the study was partly precipitated by a report presented to the Developmental Disabilities Office (DDO) by the Training and Technical Assistance Project in Lubbock, Texas. That report, based on a survey of the membership of State DD Councils, concluded that the

average DD Council member was a 47 year old White male. The report further noted the low percentage of minorities represented in DD Council memberships.[1] Other studies also pointed to the lack of minority participation at various levels of society.[2] Thus, there was historical precedence for DHEW-DDO to seek answers to questions related to minority participation.

Study Approach

Two basic approaches were used in the study to obtain information on the subject: A series of meetings, and a mailed questionnaire.

The primary means for obtaining information on and about minorities during the first year centered around a series of fourteen meetings held in cities judged to be accessible to at least one of the minority populations as defined in the study. These cities were: San Francisco and Los Angeles, California; Seattle, Washington; Phoenix, Arizona; Albuquerque, New Mexico; Dallas, Texas; New Orleans, Louisiana; Rapid City, South Dakota; Kansas City, Missouri; Nashville, Tennessee; Atlanta, Georgia; Chicago, Illinois; Philadelphia, Pennsylvania; and Washington, D.C.

Identification and Selection of Meeting Participants

In attempting to establish an accessible route for identifying

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[1] Linda D. Baucom and Donald Stedman, "A Survey of the Membership of State and Territorial Developmental Disabilities Councils: Relevant Characteristics and Observations." Study sponsored by Division of Developmental Disabilities, Office of Human Development Service, Department of Health, Education, and Welfare, Washington, D.C. (1974).

[2] See for example, Foskett, J.M., Social Structure and Social Participation (1954); Freeman, H., Correlates of Membership in Voluntary Associations (1954); Gittell, M., Participants and Participation, A Study of School Policy in New York City (1962); Mathews, D.R., and Prorthro, J.W., Negroes and the New Negroes and the New Southern Politics, (1966); Nie, N.H., Powell, G.B., Jr., and Prewett, K., Social Structure and Political Participation (1969); Nie, N.H. and Verba, S., Participation in America: Political Democracy and Social Equality, (1972); Robinson, J.P., Measures of Occupational Attitudes and Occupational Characteristics, (1969); and Stromquist, N.P., Antecendent and Concurrent Conditions of Participation: The Case of Participatory Educational Planning, (1977).

minorities to participate in the meetings, the following procedural difficulties were encountered:

1. There were no acceptable national incidence or prevalence rates on DD in minority populations. Thus not only was distribution of disabilities among minorities unknown, but the distribution by region and state were further unknowns. Consequently, we could not establish which disability required greater representation at the meetings due to its possibly higher incidence in the minority population.
2. There is no unified or comprehensive source for identification of minority consumers within the DD system. Thus the project was unable to randomly select persons for participation in the meetings.

In view of this, the project implemented a purposive selection process for obtaining participants for the meetings. This evolved into a type of case study approach. That is, the project identified characteristics or factors upon which to select minority persons for attendance at the meetings (which were limited to 35 participants). These factors were:

1. Ethnicity. Attempts were made to obtain participants from all minority groups in the study.
2. Consumer status. Parent of a disabled child, disabled person, concerned individual.
3. Type of disability. Mental retardation, epilepsy, etc.
4. Status of involvement in the DD movement. Staff, member of council or board, non-board member.

Names and/or identification of minority persons based on these factors or characteristics came from two principal sources:

1. "Within the DD movement," e.g., providers of services (DD Councils, United Cerebral Palsy, National Association for Retarded Citizens, Head Start programs).

2. "Outside of" the DD movement, e.g., various organizations concerned with the quality of services to minorities (National Urban League, Welfare Rights Organization, Aspira, Inc., Asian, Inc., Tribal Councils).

In selecting persons for attendance, all factors previously described were considered and thus, each disability and each minority population had representation at the meetings.

Format for Meetings

Separate meetings were held for parents/consumers and for agency personnel in each city. Again, because their distribution by region and state and type of disability served were then relatively unknown, no sampling procedures were possible for selection of agency participants. However, the project did use the following descriptors (when known or indicated) in inviting and/or selecting agency personnel for the meetings:

1. public or private status;
2. state or local agency;
3. type of service offered (i.e., diagnostic, referral, counseling, etc.);
4. type of disability served (mental retardation, epilepsy, cerebral palsy, autism).

Thus, a somewhat purposive selection process was again used.

A set of unstructured questions devised to generate discussion at the service provider sessions were designed to elicit oral information on: agency perception of the need for minority participation; crucial service needs of the minority DD population; minority population understanding of developmental disabilities; and questions agencies felt should be asked of minority consumers via the questionnaire. It also gave them an opportunity to express themselves on minority participation. (See Appendix G.)

A set of unstructured questions were also developed for use with parents and consumers and were designed to elicit perceptions and feelings

on service availability and adequacy, minority participation and barriers to participation (see Appendix G). The session with parent/consumers provides the only input in the study directly from this group.

During the meetings, minority parents/consumers and service providers raised their own issues and concerns, identifying problem areas and pinpointing factors which warranted questioning via the survey. These issues were either agreed to by most of the participants and/or were controversial in nature, yet showed insight into the DD service delivery system, and/or minority parent/consumer feelings about this system.

The meetings were unique in that they involved the target population in discussing strategies for change. The discussion format guaranteed a certain number of representative responses from grassroots consumers, and verbal questioning enabled us to gather a record of responses from those persons who were directly affected by the DD movement.

The results of the meetings were published in a staff paper, "The Delivery of Developmental Disability Services to Minority Persons: A Two-Fold Perspective" and has had wide distribution.

Supportive Activities

The project's programmatic activities during the second year were placed into three major categories as follows:

1) serving as a resource center for the development, identification and dissemination of information on minority populations and their disabilities (see Appendix A);
2) serving as a training resource for organizations and groups on minority needs;
3) revision of the survey questionnaire

A number of papers were written (see Appendix B). Two papers have been published, the first in Abstracts in Social Work and the second by the

Research Training Center in Mental Retardation at Texas Tech University. In addition, four (4) volumes of references (articles and studies) on minority populations and the disabilities were compiled by project staff.

The project prepared for in-house use by the Developmental Disabilities Office (Washington, D.C.) a reference containing over one hundred names of minority professionals for use by federal, state and local government and private organizations when persons are sought for service on various panels, committees, task forces and councils.

The project also compiled a manual on the disabilities. This manual was disseminated to a limited number of minority professionals, parents, and groups/organizations concerned with services to the developmentally disabled.

As part of its resource functions on minorities, the project actively participated in national and local conferences and meetings directly or tangentially related to developmental disabilities. At these conferences and meetings project staff actively participated in an effort to increase the awareness of non-minority persons to the needs of minorities. These meetings and conferences included:

- Corporate Volunteer Advisory Board meetings of the Employment Project for the Physically Handicapped.
- Joint Developmental Services Liaison Committee of the California State Department of Rehabilitation and Developmental Services (monthly).
- The National Association for Retarded Citizens, Project Impact Training Institute.
- Annual meeting of the California Mental Health Association (June, 1978).
- University of California Advances in Neurology meeting (May, June 1978).
- Meetings of the San Francisco Aid to Retarded Citizens (monthly).
- Meetings of the San Francisco Developmental Disabilities Council

[A project staff member served on the Board of Directors of this Council (which meets monthly).]

The project gained recognition in the DD field as having expertise in the field of the developmentally disabled population. As a result, numerous requests were received to participate as panelists in conferences and to act as trainers for in-service staff education sessions. Subsequently, project staff participated in the following activities:

- Conference on Implementation of Developmental Disability Protection and Advocacy Systems (December 1977).
- National Conference on Social Welfare (May 1978).
- Conference and In-service Training Session sponsored by the University of California and the Golden Gate Regional Center entitled, "A Multi-Cultural Perspective on Serving the Developmentally Disabled." Project Staff participated in planning the conference and served as resource panelists for one of the workshops (May 1978).
- Tri-Counties Regional Center (CA) Fifth Annual Scientific Symposium on Developmental Disabilities. Project Staff presented information on the needs of Hispanic populations (April 1978).
- Served as resource/consultant for the White House Conference on Handicapped Individuals, Washington, D.C. (May 1977).
- President's Committee on Mental Retardation Conference: A National Multi-Cultural Seminar on Mental Retardation Among Minority Disadvantaged Populations. Project Staff served as panelist and presenter for a general session on service needs of minority populations (October 1977).
- Golden Gate Regional Center, San Francisco, California. In-service training on cultural differences of minority clients which impact on the treatment process (January 1978).
- Visit to Navajo and Hopi Reservations. This activity was the the fulfillment of a promise made to the Native American community that project staff would visit the reservation to learn more fully what their needs were (March 1978).

Changes in the Investigation's Approach

Also during the second year, the methodology of the use of a mailed questionnaire to solicit responses was significantly altered to reflect

changes recommended by the Office of Program Reporting and Evaluation (OPRE) and the Office of Management and Budget (OMB). The changes included:

1. Greater adherence to survey design, particularly as relates to the selection of the sample sizes;
2. introduction of a control group of non-minority respondents;
3. greater emphasis on obtaining quantifiable as opposed to qualitative data;
4. implementation of the survey in two phases:

   Phase I -- survey of service providers, and

   Phase II -- survey of clients/consumers

Thus, rather than disseminating the questionnaires and analyzing the responses, as was projected for Year II and in line with the original proposal, the second year was largely spent in revising the survey plan and redesigning the questionnaire. Goals and objectives had to be reclarified. The project had to further demonstrate that the survey instruments were conceptually relevant to the modified working hypothesis and experientially related to the theoretical basis of the study.

Problematic Areas

Several areas proved problematic and prevented completion of various aspects of the study during this period. The initial purpose of the study was a fact-finding mission on the number of minorities participating in DD programs. However, as the study evolved, DHEW became increasingly interested in the subject matter and made numerous suggestions and recommendations on how the study design and questionnaire should be restructured. One such suggestion was that non-minorities be included in the study as a control group.

In order to have a study which reflected the interest of HEW, NDCS worked diligently to redesign the original study and to incorporate the suggestions and ideas which were made by the staff of OPRE. This review process necessarily lengthened the time span for getting the survey to the field.

Additionally, despite prior knowledge of the lack of existing quantitative information, it was necessary for the project to spend extra time verifying this lack of information because some reviewers of the survey plan requested that the sampling be based on actual rather than estimated or "proxy" figures on the number of minorities who are developmentally disabled, and on those being served. It was finally concluded that the only way to systematically secure the information requested was to implement the study.

Other problems or obstacles seemed to stem from the misconception of some people in the DD field about the study's goals and objectives. For example, some agencies viewed the study as an affirmative action study and thus were quick to assure us (when we requested information on the availability of data) that they served minorities and that members of these populations were well represented on their boards.

Further, with all of the resources which compile and report information on minorities, either directly or indirectly related to developmental disabilities, it might be possible to conclude that an assessment of minority participation would be an easy task. However, the information available from these resources is fragmented and when put together still does not yield a comprehensive picture of minority participation.

The key mechanism for gathering data on the developmentally disabled population is established in the legislation. That mechanism is the State

DD Councils. However, the Councils collect only that data which is specified in the guidelines. Racial ethnic data is not so specified.[3]

Parameters of the Investigation

Information about the quality and nature of services offered to the developmentally disabled should be obtained ideally from at least two sources, namely, service providers and consumers. Because of the lengthy review process (approximately 18 months), the present study is mainly concerned with gathering information from service providers. However, some information based on participant observation was obtained from clients at the nationwide meetings.*

The time it would take to resolve the methodological difficulties associated with the consumer survey (e.g., the problem of drawing a sample from case records of agencies who differed in their recordkeeping, and the confidentiality aspects of the survey) would mean that the study would be unduly prolonged. For these reasons, the consumer survey was not conducted. Instead it was decided to concentrate on completing the service provider survey.

It is clear that there can be a great divergence of opinion between service providers and service consumers on matters such as the quality and extent of service. Therefore, it is important that the reader bear in mind that we are presenting details about only one side of a many-sided story.

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[3]Some states have instituted a data collection system as outlined by the Individualized Data Base Project in Los Angeles, California. Were this system in place in all states, data on client race/ethnicity would be systematically and readily retrievable.

*The nationwide meetings (held in January, February, and March of 1977) yielded comments and concerns from 500 minority consumers, parents of developmentally disabled children, and persons who were themselves disabled, regarding their participation or lack of participation in DD services.

When the survey was being designed, several questions and issues were raised. For example, are there identifiable barriers (economic, racial, cultural, or other) to minority participation in the planning, implementation, and use of DD services? What role do agencies play in establishing, maintaining, or tearing down these barriers? How much is participation a function of economic background of the family? How much does it have to do with availability of transportation? Would having bilingual staff facilitate participation? Is participation affected by the availability (or lack) of information? Are public agencies the prime providers of services to minority disabled persons? What role, if any, do private agencies play? Does size of budget affect the number of minority persons participating in programs?

These questions suggested several hypotheses. Before formulating these questions for testing, however, the project sought to establish what had previously been reported by researchers who had examined related questions and aspects of minority participation. Accordingly, a review of the literature was undertaken. This review is discussed in the following section.

III: REVIEW OF THE LITERATURE

As previously mentioned, the results of the literature review provided additional insights to assist the project in designing the survey instrument. Thus, it is appropriate to describe these results before discussing the findings of the survey and nationwide meetings.

The following review is divided into two major sections. One section focuses on research relating to the role of the agency in providing service, and the other on the role of the minority consumer in seeking service. Within each category, the relationship of related variables is explored, such as; the effect of the type of agency, budget size, existence of outreach programs, geographical location, and the presence of minority staff; and the effect of family income, number of children, area of residence, exposure to DD programs, migration, and transportation on participation in the movement. In addition, this section includes information on a research review of a related topic -- the labeling process, which leads a disproportionate number of minority children to be labeled retarded.

The following findings from the literature review deal with each of these factors. Regretably, however, most of the literature deals with retardation, particularly of a mild or functional variety, and little deals with the seriously retarded, epileptic, autistic, or cerebral palsied. There is also little directly dealing with minority participants as users of services, staff members of service agencies, or members of agency boards or commissions.

Finally, this review points to the lack of studies on how cultural differences affect the way minority persons use or do not use DD services.

These gaps point up the need to examine more closely the delivery of services to minority persons and the extent of their participation in the DD movement.

A Review of the Literature Dealing with Service Providers

Type of Agency: Both the comments at the national meetings and a review of the literature suggests that public agencies generally serve more minority group persons than do private agencies. As an example, more developmentally disabled children are enrolled in public than in private schools.

Several studies show this. For example, Ford (1975),[1] McGrath (1960)[2] and Cohen (1968)[3] have pointed out that handicapped and retarded minority students (particularly Blacks) enroll in public schools at a much higher rate than handicapped non-minority students. Others have suggested that minority group members are more likely to be found in handicapped or retarded groups. More specifically, Williams (1968)[4] reports, based on a three state study of Mexican-Americans, that Mexican-American children were enrolled in special education classes at twice their proportion in regular classes.

The same pattern of increased minority participation in the public sector shows up in the welfare services field. For example, a 1973 California Department of Health, Office of Planning and Program Analysis study, "Implementing Community Services for Developmentally Disabled Public

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[1] Ford (1975) "Analysis of 1973 Participation of Handicapped Children in Local Education Programs."

[2] McGrath et al. (1960), "Investigation of Mental Retardation in Relation to Bilingual and Subcultural Factors."

[3] Cohen (1968), "Socially Disadvantaged Americans: Slow Learners."

[4] Williams (1968), "Improving Educational Opportunities for Mexican-American Handicapped Children."

Assistance Recipients," showed that disabled persons on public assistance were more likely to be served by public social service agencies than by regional centers or private entities.

Lei et al. (1974)[5] also found that those identified and treated as mentally retarded by public agencies were predominantly minority and/or low-income individuals living in deteriorated housing, whereas those similarly handled by private clinics were predominantly middle- and upper-class non-minority group members from better residential areas. In another study, Lei et al. (1976) found that disabled minority individuals of lower socio-economic background were more likely to be served by public agencies than middle income non-minority disabled patients, who were more apt to have private care.

In sum, these studies suggest a positive association between type of agency (public versus private) and the proportion of developmentally disabled minority persons served. Minority group members are more likely to seek and receive services from public agencies.

Size of Agency Budget: As might be suspected intuitively, the literature indicates that agencies with larger budgets are better able to serve a larger clientele and undertake outreach programs than agencies with low budgets. Numerous studies point to the failure of agencies to serve clientele because of budget restrictions. For example, Sontag (1972)[6] points to the failure of agencies serving American Indian and Alaskan Native populations to provide proper education and health services for this reason.

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[5] Lei et al. (1974), "Agency-Labeled Mentally Retarded Persons in a Metropolitan Area: An Ecological Study."

[6] Sontag (1972), "Programs for American Indians and Alaskan Natives."

Similarly, Watson (1972)[7] notes the low budgetary levels of agencies in predominantly rural states due to the allocation of federal funds based on population, and he discusses their limitations.

Outreach Programs: These budgetary limitations in turn reduce the ability of agencies to fund outreach programs, which are particularly effective in reaching the minority disabled. Often this lack of outreach means potential minority clients don't get served, since they are not aware of the services available. Several research reports indicate this. For example, when Justice et al. (1971)[8] studied 171 community-labeled retardates with IQ's less than 70, he found that the minority parents of the disabled children were largely unaware of the existence of service agencies. Similarly, a study by the Western Interstate Commission for Higher Education (1969)[9] on retardation pointed up the need for specialized outreach programs to serve the minority disabled effectively. Two federally funded projects, Project Star sponsored by the National Urban League (Long, 1973), and Project Impact sponsored by the National Association for Retarded Citizens (Long, 1978) echoed the same theme.

After evaluating several outreach programs of existing agencies in which local community members were employed, they both concluded in separate studies that services to minorities increased with the expansion of outreach programs.

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[7]Watson (1972), "Special Problems and Special Aids in Resolving Special Needs in Rural Areas."

[8]Justice et al. (1971), "Problems Reported by Parents of Mentally Retarded Children: Who Helps."

[9]Western Interstate Commission for Higher Education (1969), "Four Corners Mental Retardation Project: Training and Use of Indigenous Aides in a Sparsely Populated, Economically Depressed Region."

[10]Long (1973), "A Final Report on Project STAR (Serving to Advance Rehabilitation)." National Urban League, Family Service Association of America, National Association for Retarded Children, Social and Rehabilitation Services, DHEW, and "Full Citizenship for Low-Income Mentally Retarded." Project Impact, National Association for Retarded Citizens, 1978.

These outreach programs have also been found to be effective in helping the minority disabled. For example, Cawley (1968)[11] found that the learning aptitudes of slow, average, and mentally retarded low-income children enrolled in Project Head Start increased significantly for all groups, as measured by tests of motor speed and precision, preconscious visual attention span for objects, oral communication, and orientation. This increase he attributed to their Head Start experiences. Effective outreach in Head Start programs can bring children who may be developmentally disabled into the mainstream. On the basis of these studies, we believe that a positive relationship exists between outreach programs and the number of persons served.

Type of Positions Held by Minority Persons

Other research suggests that if minority members are in decision-making positions in agencies they will encourage minority disabled persons to learn about and use DD services, and will do so to a greater extent than non-minority members. Such research has been undertaken in response to the thrust for affirmative action hiring resulting from the Civil Rights movement. The results support the Civil Rights philosophy that such hiring is important, since minority staff members will serve minority needs more effectively. For example, studies by Sanchez (1972)[12] and the California Department of Health, Office of Planning and Program Analysis (1973) analyzed the recruitment and retention of minority staff members in the Urban League (Long 1973). Both studies concluded there is a need for minority staff members.

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[11] Cawley (1968), "Learning Aptitudes Among Pre-school Children of Different Intellectual Levels."

[12] Sanchez (1972), "Reaching the Developmentally Disabled Among Special Disadvantaged Groups."

Geographical Location of Service Agencies: The geographic location of a service agency has also been shown to have an impact on the number of minority persons served. Specifically, as hypothesized in this study and suggested by the data, agencies in urban settings serve more minority disabled persons than those in rural settings, partly due to a greater concentration of minorities in urban areas, and the larger size of urban agency budgets. As previously noted, Watson's 1972 study points up the low funding levels of agencies in rural states, as a result of the allocation of federal funds by population. Also, Sontag (1972) and Reschly, et al. (1976)[13] suggest that the extent of DD service is significantly related to geographic locale.

Presence or Absence of Minority Staff: Another study assumption, supported by the research, is that the number of minority persons served increases with the number of minority staff members in an agency. The probable reason is that minority staff members can be more sensitive to minority needs and more effective in encouraging them to use DD services, since they are better able to identify with minority clients. In both Project Star and Project Impact, (Long 1973 & 1978) concluded that the number of minority service users of two outreach programs increased due to minority staff participation. Chomor et al. (1974)[14] found in a project for the sightless staffed by Japanese Americans that having an ethnically homogenous group of staffers involved in service delivery heightened clientele receptivity and identification.

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[13] Reschly, et al. (1976), "Ethnicity, Geographic Locale, Age, Sex, and Urban-Rural Residence as Variables in the Prevalence of Mild Mental Retardation."

[14] Chomor et al. (1974), "Japanese American Sightless Institute Project."

A similar conclusion was reached at the proceedings of the Symposium on the Minority DD Citizen (San Francisco) and Inter-Tribal Symposium, (Arizona) both held in 1976. In both cases, participants agreed that having minority staff would increase the number of minority persons served.

Other studies have emphasized the importance of minority staff sensitivity in increasing the number of minority disabled served. For example, a study funded by the Department of Health, Education, and Welfare, Social Rehabilitation Services (1972) concluded that minority staff members were more sensitive to minority needs than non-minority staff, and thus better able to identify minority problems and formulate productive strategies to solve them.

A Review of the Literature Dealing with Minority Consumers

Income of Family: Both a review of the literature and the response at the national meetings indicate a relationship between income status and minority participation in DD programs. More specifically, middle- and upper-income minority parents of developmentally disabled children are more likely to take part in programs than lower-income minority parents. Frequently, this occurs because low-income consumers lack the financial resources to get to the agency to participate, or are unaware of the availability of services, due to a lifestyle restricted by their financial status.

This theme was reiterated at the national meetings. For example, some parents stated that they could not attend meetings and programs concerning DD services because they could not afford to pay a sitter. And much literature bears on this point. In interviews with parents of retarded children from 171 communities, Justice et al. (1971) found many of them were unaware of services for the disabled. Although many indicated

they would use such services if they knew about them, they also voiced their lack of economic means to participate. Similarly, many Mexican-Americans at a 1978 Santa Barbara Symposium[15] given by the Tri-Counties Regional Center on Developmental Disabilities, said they were limited in becoming more active in DD programs because of financial reasons. Primarily, they lacked the financial resources to pay for child care, which was necessary since many fathers did not see baby-sitting as part of their role.

Low-income minority persons are also less likely to use institutional services as a solution to DD problems, as Edgerton and Karno (1972)[16] found when they interviewed 441 Mexican-Americans in two urban sub-communities and 226 Anglo-Americans in one sub-community. They found that low-income compared to middle income Mexican-American parents were more likely to keep their retarded child at home than in an institution, while middle class parents were more likely to participate in agency services and programs. Similarly, Gwen (1968)[17] found that middle class Black parents, like middle-class Anglicized Mexican-American parents tended to seek services and institutionalize their children more frequently than lower-class Black parents did.

Other studies have found an association between low-income status and developmental disabilities. For instance, a report by the National Asso-

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[15] Santa Barbara Symposium (1978), "Facilitating Communication Between Clients, Parents, Professionals, and Service Providers."

[16] Edgerton and Karno (1972), "Community Attitudes Towards Hospital Care of Mentally Retarded."

[17] Gwen (1968), "Determinants of Negro Family Decisions in Management of Retardation."

ciation for Retarded Citizens (NARC, 1973)[18] stressed that children from low-income families are more likely to be retarded than children from higher income families. In turn, such families are less apt to seek aid from NARC and other programs, and this pattern is due to traditional enlistment approaches which discourage low-income minority participation. For more minority participation, NARC suggested that churches, schools, clinics, and other social agencies develop more outreach programs to contact such families.

This theme of low-income status associated with developmental disabilities, such as mental retardation, is emphasized even more strongly by Heber et al. (1972)[19] who argue that mentally retarded, low-income minority parents are likely to produce another generation of retarded children. However, the study also suggests that the provision of services can ameliorate the problem, since it was found that after several types of intervention -- a maternal rehabilitation program, an infant intervention program, and adult education classes for parents -- the IQ scores of the treated parents rose considerably. Similarly, Cawley's study (1968) of children in Head Start programs indicated that the exposure to this program considerably improved the level of functioning of pre-school age mentally retarded minority children.

Another study by Reschly et al. (1976) pointed to an association between mild mental retardation, ethnicity, and geographic locale, based on the administration of the revised Wechsler Intelligence Scale for Children

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[18] NARC (1973), "Plan for Everyone: The Involvement of Low Income and Minority Members."

[19] Heber et al. (1972), "Retardation of Families at Risk for Mental Retardation."

to a random sample of 950 children of Anglo, Black, Mexican-American, and American Indian ethnicity.

In sum, these studies show that low-income status is associated with an increase in disability status and with a reduced use of DD services.

Number of Children: The literature was also reviewed to determine if there was a relationship between the number of children and parent's participation in DD services. Although none of the literature addresses this topic, a discussion of this topic at the national meetings and at the Tri-Counties Regional Center Symposium suggested that families with several children had more difficulty participating in DD programs because of the costs of child care requirements. Several families with several children indicated they couldn't participate without the aid of relatives.

Area of Residence: Area of residence also affects consumer participation in DD activities, according to the literature review. Those living in urban areas or near agencies were more apt to participate. For example, Sontag (1972) found that although American Indians and Alaskan Natives did not receive adequate services, those living closer to agencies were served more frequently. Reschly et al. (1976) found that minority persons in rural locations where medical and service agencies are inaccessible may not be able to seek services. In some cases the study found this failure to seek services contributed to the development of mental retardation.

However, recently, some government efforts have begun to change this problem of rural inaccessibility. In 1974, the Department of Health, Education, and Welfare commissioned the Office of Human Development Services (OHDS) to develop the "Year of Achievement" advocacy program to administer services to Native American and other minority disabled in rural areas who lacked access to services. Under this program, nine federal agencies operated to meet these needs.

Exposure to DD Programs: The literature, as well as the comments of consumers at the national meetings and the Tri-Counties Regional Centers Conference, has also supported the assumption of the study that consumer participation in DD services increased with exposure to, or knowledge of services. Also, it supports the assumption that outreach programs provide a useful means of reaching the minority disabled.

Some of these studies have already been cited. For example, the Western Interstate Commission for Higher Education (1969) suggested a need for specialized outreach programs, particularly using local minority persons to serve the disabled effectively. In Project Impact (1978) and Project Star (1973), Long evaluated the effectiveness of such outreach programs.

Similarly, Wyatt et al. (1977)[20] found that when therapists extended their efforts to culturally different families, the parents -- in this case, of Black high risk adolescents -- were more apt to participate in DD programs.

Other studies have suggested that if the outreach services were available, minority parents would be more likely to use them. For example, Justice et al. (1971) found that minority parents of disabled children were often unaware of service programs but would take advantage of them if they knew they were available.

In a similar study, Eyman et al. (1977)[21] indicated a need for increased communication about available community resources, so that minor-

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[20] Waytt et al. (1977), "The Readjustment of Black High Risk Adolescents to the Community."

[21] Eyman et al. (1977), "Use of Alternative Living Plans for Developmentally Disabled Children by Minority Parents."

ity parents could participate in DD programs. Chomor et al. (1974) found that cultural and historical barriers within the Japanese community resulted in an underutilization of agency services, and recommended that the agency address the community's cultural orientation and needs to increase its effectiveness in serving the community. Roger (1967)[22] found that the Navajo Indians developed a more positive attitude towards using DD services when the Navajo Rehabilitation Project was established.

Migration: Some research was also done to determine if migrants from other countries or regions were less likely to use DD services, as assumed by the study. This issue was raised at the national meetings, where many parents of Mexican-American extraction stated that language was a barrier to receiving services in areas where service agencies did not use Spanish. Those with relatives in Mexico and who were more culturally oriented to Mexican values were especially disadvantaged. However, no literature was found addressing this topic.

Transportation: Similarly, no studies were found dealing with the relationship between transportation and participation in DD activities, although comments at the meetings indicated consumers in rural areas were quite concerned about this and reported that they could not obtain services because agencies were located too far from their homes. Native Americans living on reservations in Arizona, New Mexico, Utah, South Dakota, and North Dakota expressed similar concerns.

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22 Roger (1967), "Disabled Navajo Indians and Rehabilitation: An Anthropological Overview."

A Review of the Literature Dealing with the Issue of Labeling and the Developmentally Disabled

The issue of labeling and its effects on the minority consumer is an important one, since minority individuals are disproportionalely labeled as developmentally disabled, and notably as retarded. While this label opens up the opportunity for services, it also may cast the individual in a certain role, sometimes inappropriately, because of cultural differences interpreted as intellectual disadvantages. Since this labeling process is closely tied to the issue of providing DD services, it is an important process to consider.

Much of this labeling goes on in the public schools, which tend to rely solely on IQ test scores in determining intelligence without considering the effect of culture, socio-economic status, and environment on these scores.

Numerous studies have pointed out the inadequacy of standardized test IQ norms in determining intelligence and have pointed to the adverse consequences of inappropriately labeling minority children as retarded. For example, Mercer has supported this observation in a series of studies (1971, 1972, 1974, 1975).[23]

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[23] Mercer (1971), "Pluralistic Diagnosis in the Evaluation of Black and and Chicano Children: A procedure for Taking Sociocultural Variables into Account in Clinical Assessment."

Mercer (1972), "Socio-cultural Factors in the Educational Evaluation of Black and Chicano Children."

Mercer (1974), "A Policy Statement on Assessment Procedures and the Rights of Children."

Mercer (1975), "New Assessment Techniques for Mentally Retarded and Culturally Different Children: A Conversation with Jane R. Mercer."

This labeling in turn adversely affects the self-esteem of the labeled children and may itself interfere with their cognitive behavior, as Jones (1973)[24] indicates.

Other researchers who have reached similar conclusions are McGrath (1960),[25] Cohen (1968),[26] Edwards (1974),[27] Chandler (1969),[28] and Chandler and Plakos (1970).[29]

To date, according to the literature, the schools have made some efforts to assist retarded children, but in general, it has ignored those with other developmental disabilities. For example, numerous studies describe efforts made by various public school systems to serve the mentally retarded child through new educational approaches. Some of these studies, which report progress with bi-cultural groups, such as Mexican-Americans, Chinese-Americans, Puerto Ricans, and American-Indians, as well

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[24] Jones (1973), "Delivery of Special Services to Young Black Children."

[25] ibid.

[26] ibid.

[27] Edwards (1974), "Blacks vs. Whites: When Race is a Relevant Variable."

[28] Chandler (1970), "An Investigation of Spanish-Speaking Pupils Placed in Classes for the Mentally Retarded."

[29] Chandler and Plakos (1969), "Spanish-Speaking Pupils Classified as Educable Mentally Retarded."

as Blacks, include Ramirez et al. (1974),[30] Grant (1972),[31] Castaneda et al. (1974),[32] Evards et al. (1974),[33] Heath (1972,[34] and Johnson (1967).[35]

As reported by some investigators, such as Noar (1967),[36] the schools have used various methods to assist teachers in upgrading educational opportunities for the disadvantaged, such as providing up-to-date summaries of educational research findings and their teaching implications, as well as suggested procedures to aid the disadvantaged child at various age levels. These materials have also been used to change teachers' attitudes, so they are more positive to the disabled.

Past et al. (1966)[37] has similarly pointed to the need teachers have for additional training when they work with students from linguistically and culturally impoverished areas, since they need to be able to understand, write, and speak the students' language in order to recognize the thought processes of these students and effectively communicate with them.

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[30] Ramirez et al. (1974), "New Approaches to Bilingual-Bicultural Education."

[31] Grant (1972), "Proceedings of a Workshop on the Preparation of Personnel: Education of Bilingual Hearing-Impaired Children."

[32] Castaneda et al. (1974), "New Approaches to Bilingual Education."

[33] Evards et al. (1974), "Development of Local Language Norms for Papago Indians, Mexican-Americans, Blacks, and Anglos."

[34] Heath (1972), "Red, Brown and Black Demands for Better Education."

[35] Johnson (1967), "Teaching Culturally Disadvantaged Pupils (Grades K-12), Unit IV: The Culturally Disadvantaged Mexican-American, Puerto Rican, Caucasian, and American Indian Pupil."

[36] Noar (1967), "Teaching the Disadvantaged."

[37] Past et al. (1966), "Bilingualism: From the Viewpoint of Recruitment and Preparation of Bilingual Teachers."

Often the studies themselves contribute to the labeling process by reinforcing the notion that minority students, particularly Black and Spanish-speaking, are more apt to be retarded and therefore more inferior in their functioning to White children. For example, Adams et al. (1973)[38] tested 50 Black and 59 Caucasian children ages 4-17, on the Vineland Social Maturity Scale and concluded that impairment varied as a function of race, since the Black boys scored lower in IQ and were more apt to be classified as impaired, very impaired, or border line than Whites. Similarly, Eisenberg (1967)[39] found that the retardation rate was twice as high for boys as girls and three times higher for Black children as Whites. Casso (1976)[40] found that Mexican-American children were more highly represented than Whites in educable mentally retarded classes becuase of their low IQ scores.

However, these White-minority differences may often be due to socio-cultural differences. For example, Lei et al. (1972)[41] suggests that Mexican-American minority children are behaviorally retarded because of their socio-cultural background, although he feels a deficiency in adapting to the standard culture is a reasonable criteria to use in determining mental retardation. Others who emphasize these socio-cultural factors are

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[38] Adams et al. (1973), "Ethnic Background, Measured Intelligence, and Adaptive Behavior Scores in Mentally Retarded Children."

[39] Eisenberg (1967), "The Epidemiology of Reading Retardation and a Program for Preventive Intervention."

[40] Casso (1976), "A Descriptive Study of Three Legal Challenges for Placing Mexican-Americans and Other Linguistically and Culturally Different Children into Educably Mentally Retarded Classes."

[41] Lei et al. (1972), "Family Socio-Cultural Background and the Behavioral Retardation of Children."

Jensen (1969),[42] Alley et al. (1970),[43] Mukherjee et al. (1976),[44] Cleland et al. (1967),[45] Affleck (1967),[46] Panda (1974),[47] Stewart (1976),[48] Alford (1974),[49] and Loquet.[50]

Because of such socio-cultural disadvantages, some researchers have been more apt to categorize some minority children as educable mentally retarded rather than learning disabled. For example, Franks (1971)[51] investigated a sample of 274 educable mentally retarded and 215 learning disabled Black children representing eleven school districts and found that more Black children are educable retarded than have learning disabilities. Others taking a similar position are Seagoe (1971),[52] Smith (1969),[53] and Mann (1969).[54]

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[42]Jensen (1969), "How Much Can We Boost IQ and Scholastic Achievement."

[43]Alley et al. (1970, "Comparative Perceptive Motor Performance of Negro and White Young Mental Retardates."

[44]Mukherjee et al. (1976), "Measurements of Intellectual Potential of Mexican-American School-Age Children."

[45]Cleland et al. (1967), "Climatological Influences in Mental Deficiency as Related to Three Ethnic Groups."

[46]Affleck (1967), "Reactions to Marginality: A Study of Mentally Retarded and Ethnic Minorities."

[47]Panda (1974), "Effects of Race and Sex on Attribution of Intellectual Achievement: Responsibility for Success and Failure Situations Among Educable Mentally Retarded Children."

[48]Stewart (1976), "Effects of Sex and Ethnic Variables on the Profiles of the Illinois Test of Psycholinguistics and Wechsler Intelligence Scales for Children."

[49]Alford (1974), "Music and the Mentally Retarded Ethnic Minority Child."

[50]Loquet (1973), "Socio-Cultural Deprivation or Difference."

[51]Franks (1971), "Ethnic and Social Status Characteristics of Children in Educable Mentally Retarded and Learning Disabilities Classes."

[52]Seagoe (1971), "Children's Play in Three American Subcultures."

[53]Smith (1969), "Intellectual Difference in Negro and White Mental Defectives."

[54]Mann (1969), "Modifying the Behavior of Negro Educable Mentally Retarded Boys, Through Group Counseling Procedures."

In summary, the foregoing discussion of the literature touches all the problems and needs identified by Naomi Gray (1977) in the proceedings of a Symposium on the Minority Developmentally Disabled Citizen held in San Francisco. The Symposium was sponsored by Asian, Incorporated; Black Child DD Project of New Dimensions in Community Service, Inc.; Minority Affairs Coalition; and Project Impact, National Association for Retarded Citizens. The wide range of concerns were expressed by minority consumers and professionals attending the Symposium.[55]

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[55]Gray (1977), "Proceedings of a Symposium on the Minority Developmentally Disabled Citizen, New Dimensions In Community Service, Inc.

IV: MAJOR FINDINGS

Characteristics of Agencies Serving the Disabled

The typical agency* serving the developmentally disabled in this country is a private non-profit organization (see Figure 5) that has been serving the disabled for over 10 years, and has the disabled as its primary focus of service delivery (about 90 percent of clients served by agencies have a developmental disability). The typical agency lists the state government as its largest source of income (see Figure 6) and generally has a budget of under $100,000 (see Figure 7). It is located in a rural area (see Figure 8) and the total population in its catchment area can be anywhere from very small (under 49,000) to very large (over 500,000).

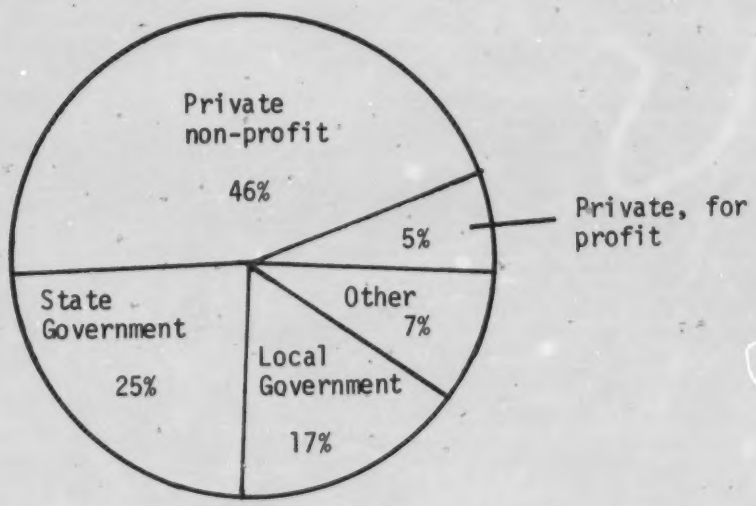

Figure 5: Percentage Distribution by Agency Type.

*By "typical agency" we mean the most frequently occurring type of agency with respect to the variable being considered.

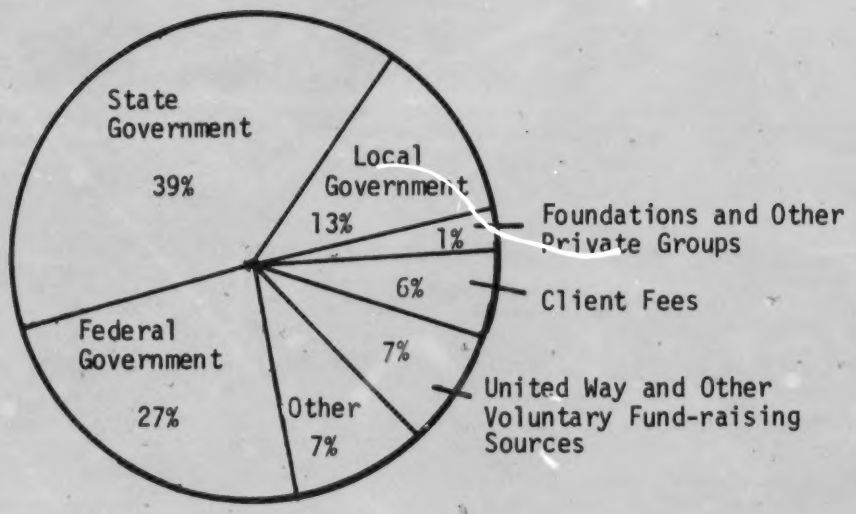

Figure 6: Percentage Distribution of Agencies by Largest Source of Funding.

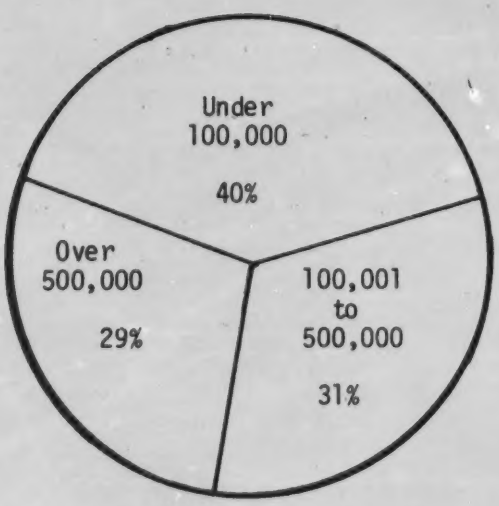

Figure 7: Percentage Distribution of Agencies by Size of Annual Budget for Developmentally Disabled.

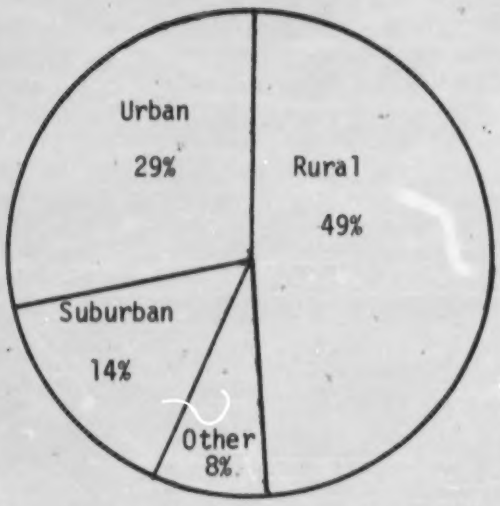

Figure 8: Percentage Distribution of Agencies by Location of Agencies.

State government agencies are more likely than private and other agencies to: (i) have been serving the disabled for over 10 years, (ii) list the Federal Government as their largest source of funding, (iii) be located in rural areas, and (iv) be in areas with a high proportion of minority persons.

Board Membership and Staffing

The typical agency has a policy or decision-making board with about 14 members, of whom approximately 2 are minority persons and none is developmentally disabled. It has a paid staff of 10 to 20 persons, but only about 4 percent are developmentally disabled. About 20 percent of the staff are minority persons.

It recruits its staff mainly through the media -- newspapers, radio, TV -- and provides no in-service training for its staff on the cultural attitudes and expectations of minority group members, mainly because there are usually no major minority groups in its service area.

Typically, about 23 percent of the staff serves in an administrative capacity; 48 percent provide direct service; 25 percent provide clerical

support, and 4 percent outreach service. The size of staff increases with the agency's budget and with the total population in the agency's catchment area. In general, suburban agencies tend to employ more workers than rural and urban agencies. Usually the staff speaks English only, although many agencies indicate a need for staffers who speak Spanish or know sign language.

Services and Clientele

The typical agency has between 50 and 100 clients who tend to be over 20 years of age, live in their own homes within 30 miles of the agency and come to the agency mainly through other agency referrals. About 70 percent of the clients are classified as mentally retarded.

Primarily, these agencies provide "education" and "identification" services. Usually, they also have an outreach program to locate potential clients, deal with newly referred clients, and distribute information. Normally, agencies have no waiting list, and list as eligibility requirements the type of disability, age, and geographic location.

Since about one-half of all agencies are private, the majority of clients (54 percent) are associated with private agencies. Although state government agencies on the average are larger agencies, there are fewer of them, so on the whole, fewer clients are associated with state government agencies than local government or private agencies.

Like staff size, the size of the clientele served increases with the agency's budget size and with the total population in the agency's catchment area. Agencies with a large budget are more likely to have an outreach program than an agency with a small budget.

Normally, clients do not participate to any extent in the implementation and planning of agency programs and services. They have little involvement or input on committee meetings or on parent-social worker meetings.

Thus, most client input comes through their case workers. Generally, the administrative staff has the greatest impact on planning and implementation, followed by board members, and then by direct service staff.

Level of Minority Participation

Although about 20 percent of agency staffers are minorities, they are less represented among administrative staff, where they make up only 10 percent of the staff. On the other hand, they make up about 25 percent of the outreach staff category. About 17 percent of the board members are minority persons.

An estimated 23 percent of clients are minority persons. Although the literature suggests that minority group members are faced with special obstacles and are less likely to use these services than non-minority group members, the agencies in this study generally reported that minority persons know about and use their services to the fullest extent possible. Where their clients don't, agencies report that the major obstacles to use of services are a lack of information about the agency, a lack of adequate transportation, or a concern with survival issues that particularly affect minority families.

The pattern of minority participation in the agencies' affairs shows many expected associations. For example, some of the major associations observed are:

- The proportion of minority persons in an agency's catchment area is positively correlated with the number of minority staff and the number of minority clients. The larger the minority groups represented in the area, the greater the number of minority staffers and minority clients.

- Variables such as budget size and type of agency, which are associated with the total number of clients, are similarly associated with the number of minority clients. For example, agencies with larger budgets, in urban areas, or public in status, tend to serve a larger number of minority clients.
- Agencies that seek to reach minorities through an outreach program have more minority clients than agencies that use no such method.
- The size of the minority clientele is positively correlated with the number of minority staff persons and board members. The larger the minority clientele, the greater the number of minority staffers and board members.

Regional Differences

There is appreciable regional variation in many variables, and much of it is due to demographic variation. For example, the number of clients per agency roughly reflects the regional population variation. Agencies with larger clientele tend to be in regions with larger populations. Also, the percentage of minority staff and clients tends to vary with regional variation in the percentage of minority people. As the percentage of minority group members in an area goes up, so does the percentage of minority group members served as clients or working on staff.

However, there is little regional variation in how long agencies have been serving the developmentally disabled, in the size of their paid staff, in whether they have a policy or decision-making board, in the size of the decision-making board, and in the relative impact on planning of administrative staff, direct service staff and board members.

Limitations of Survey

Certain limitations of the study ought to be borne in mind as one tries to interpret and generalize the above findings:

1. Despite our intensive follow-up efforts, the response rate of agencies to our questionnaire was about 50%. This means that our data will be biased if there are appreciable differences between respondents and non-respondents. We have no way at present of estimating this bias because we did not conduct a follow-up study of non-respondents.
2. There is considerable variation in the record-keeping systems of agencies contacted. In some cases, agencies did not keep certain data or make the breakdowns sought in the questionnaire and, as a result, were unable to fill in all items.
3. In the present study, there is not systematic input from disabled persons who are not served by any agency. Thus, an important set of data on minority participation in the DD movement is missing from our account.

Due to these limitations, the present study should be regarded as only a partial attack on the problem of assessing the state of the art in the DD movement and minority participation in it. However, since this is a field where data is solely lacking, the data we have gathered should be helpful in furthering understanding of minority participation in the DD field. In addition, since the survey includes data on the non-minority disabled, it should increase understanding of the DD field generally.

This section has provided a summary of the major findings about minority participation in the DD movement and the agencies serving the disabled.

The following sections present the procedures and detailed findings of the study.

V. STUDY APPROACH: BACKGROUND AND PROCEDURES

This study was designed to assess the extent and nature of the services offered to the developmentally disabled, and particularly to minority groups, by various service organizations or agencies. The principal data-gathering tools were a series of nationwide meetings with service consumers and providers, and a 40-item questionnaire mailed to service providers (agencies). The methodology used in gathering data from each source is described in this section.

The major limitations of each method are discussed in Appendix D of this report.

Nationwide Meetings

In approaching our task we conducted a thorough review of the literature and of federal reports[1] on the DD movement in order to learn what data existed and what issues and perspectives were current in the field. A summary of this review has already been presented in this report. Because of our concern about the level of minority participation in the DD movement, we also convened a series of nationwide meetings with service consumers and parents of developmentally disabled persons, the vast majority

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[1]The federal agencies from which information was obtained included the Center for Minority Group Mental Health of the National Institute of Mental Health; U.S. Census Bureau; U.S. Civil Rights Commission; American Society for Allied Health Professionals; Rehabilitation Services Administration; Bureau for Education of the Handicapped; Office for Civil Rights; Office of Child Development, Office of Human Development Services, DHEW, Washington, DC; National Center for Health Statistics, Public Health Service, DHEW, Rockville, MD; and the Office of Research and Statistics, Social Security Administration, DHEW, Baltimore, MD. Reports discussing information received were prepared by the project under the following titles: "Estimates of the Number of Minority Developmentally Disabled Persons, Using State Prevalence Rates and 1970 Census Figures," "Preliminary Report on the Number of Minority Developmentally Disabled Persons Served by State Agencies," and "Factors Affecting Minority Participation in the Delivery of Services to the DD: A Review and Critique of the Literature." Other studies related to the work of this project are cited in the reference section of this report.

of whom were minority persons, with service providers, and with other interested parties, such as employees of DHEW. The aims of these meetings were to record first-hand (a) the perceptions of the participants on the DD movement, in general, and minority participation, in particular, (b) their recommendations for improving the quality and increasing the scope of services offered to the developmentally disabled, and (c) their contributions to the list of issues that were to be addressed in our nationwide survey of agencies.

The location of the nationwide meetings, referred to previously in Section I were held in eight of the ten geographical regions defined by DHEW. An estimated 500 persons participated in these two-session meetings, in which the morning sessions were aimed at obtaining input from parents and developmentally disabled persons, and the afternoon sessions were aimed at obtaining input from agency/organization representatives.

The selection process for participants (service providers and consumers) is presented in detail in Section II, History of the Investigation.

A common set of questions was presented to the parents/consumers and another set of questions was presented to the service providers at these meetings. (see Appendix G)

Nationwide Survey

In the absence of a nationwide listing of agencies that serve the developmentally disabled, we conducted a state by state count of agencies, using directories of services.[2] Because many states had no directories, or had directories which were out of date, additional listings were secured from many other sources.[3] The listings were reviewed for duplication and, when found, multiple listings were not counted. As best as could be determined from contacts with organizations supplying the lists, listings were not prepared in any way to systematically exclude any agency. Indeed, it appears that every effort was made to include as many agencies as possible.

A total of 23,817 agencies were identified using these procedures. By region the distribution was as follows:

Region I	1663	Region VI	927
Region II	778	Region VII	2397
Region III	3297	Region VIII	1772
Region IV	5022	Region IX	2643
Region V	4556	Region X	762

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[2]Services defined in P.L. 95-602 under "'priority services' include case management services, (such as needed social, medical, educational, follow-along, coordination of other services, information on programs and services and monitoring of the persons' progress); child development services (such as prevention, identification, and alleviation of DD in children and includes early intervention services, counseling and training of parents, early identification of DD and diagnosis and evaluation of such DD); alternative community living arrangement services (such as assisting with suitable residential arrangements and includes in-house services -- personal aides and attendants and other domestic assistance and supportive services -- family support, foster care, and group living services, respite care and staff training, placement, and maintenance services); nonvocational social-development services (such as services that will assist persons with DD in performing daily living and work activities)." The preparers of the lists of agencies which we used appeared to be guided by the federal language in the March 1977 Guidelines and Instructions for Developing and Preparing the Comprehensive State Plan for the Developmental Disabilities Program. The definition of an agency, which we gave earlier, was extracted from these guidelines.

[3]These sources include the National Center for Health Statistics, University Affiliated Program, Society for Autistic Children, March of Dimes, Epilepsy Foundation of America, Association for Retarded Citizens, United Cerebral Palsy Association, state and local DD councils, DHEW regional offices, and designated state DD agencies.

As in most studies of this kind, the sample size was determined mainly by the unit cost of sampling (relative to the available budget) and by the desired level of precision in estimating parameters. In Appendix E we detail our reasons for selecting a sample of 1,200, and for distributing the sample across regions in a certain way. The number of agencies in the sample from the 10 regions were as follows:

Regions	Sample Size (n_j)
I	50
II	50
III	170
IV	310
V	190
VI	70
VII	80
VIII	70
IX	180
X	30

In this sampling plan the standard error of measurement for each region is less than 10 percent. It reaches this level only for Region X, and we found this very acceptable. In estimating national rather than regional parameters, the standard error of measurement with a sample size of 1,200 would be about 1.4 percent.

The content and format of the survey instrument were based on inputs from our review of the literature, federal reports and guidelines, from participants (both consumers and agency representatives) in the nationwide meetings, from staff at the funding source, and from volunteer and paid consultants. The instrument, which is given in Appendix F, was ultimately approved for dissemination by the U.S. Office of Management and Budget.

The questionnaire was divided into five sections: Section I, Agency Information, contained items on type of agency, budget, etc.; Section II,

Staffing, contained items assessing the distribution of employees by job category, ethnicity, and DD status, and methods used to recruit staff; Section III, Services, contained items assessing the number of clients by type of disability, methods of referral, etc.; Section IV, Participation, assessed the distribution of board members by ethnicity and DD status, how these board members were elected, etc.; and Section V, Additional Comments, gave respondents an opportunity to make open-ended comments about the unmet service needs of the minority developmentally disabled population in the catchment area.

Wherever possible, questions were constructed with the goal of obtaining quantifiable data. In the next section we will group the responses to the questionnaire under five separate headings and in line with our objectives.

A. Structure and demographic characteristics of DD agencies,
B. Extent and the nature of services provided by agencies,
C. Characteristics of clientele,
D. Extent and level of minority participation,
E. Unmet needs of minority DD persons.

In developing the codebook for the study, the decision was made to recode numerical responses to the questionnaire, such as the number of paid employees, into an ordinal scale. Typically the ordinal scale values range from 0 to 8, with 9 being used as the code for missing values. Coding was actually carried out by members of the project staff and by students hired specifically for this purpose.

The questionnaires were mailed to agencies in March 1979, and responses were collected until August 16, 1979. During this period, extensive follow-up activities were conducted among the non-respondents. These follow-up procedures included sending one mailgram, three additional mailings of the questionnaire, and telephone calls.

After the responses were coded, they were sent to the computing center (SCIP) at Stanford University where the data were punched onto IBM cards, and where the statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS).

VI: PRESENTATION AND ANALYSIS OF THE DATA

In this section we present (a) our measurements of the precision of estimates of the most important quantities, (b) estimates of the percentage distribution of agency responses to each questionnaire item for the country as a whole (regional distributions are shown in Appendix H), and (c) cross-tabulations which show the degree of association between selected pairs of variables.

Our selection of cross-tabulations for inclusion in this report is as follows. From our list of 485 coded variables, we selected those variables that related in an important way to one or another of our objectives. We then generated over 1,000 two- and three-way cross-tabulations involving these variables. We then focused on those cross-tabulations in which the chi-square measure of association between variables was significantly large (our criterion for "significantly large" being the.05 level).* Within this reduced set of significant correlations, some appeared to be spurious and were not included in this report. The majority of the remaining significant correlations are reported here. In the verbal description which accompanies the Tables, we mention also some of those correlations that were insignificant.

Precision of Estimates

The data reported in the subsequent tables are based on 732 questionnaires. The sample sizes are thus small enough that non-trivial sampling error exists. Our method for computing estimates and their sampling errors are outlined in Appendix E. In general, one can place substantial reliance only on estimates based on the whole sample, and sampling reliability of estimates declines as the sample is sub-divided.

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*Other measures of association, such as the contingency coefficient and the phi coefficient, were computed, and they lead to essentially the same picture as the one to be described.

For example, estimates by Region are more unreliable, sometimes by a factor of 5, than estimates for the whole country. Since even rough estimates have value when there is little prior data in a field, we will report such data. The reader is warned, however, that estimates based on sub-samples should be used cautiously.

In Table 1 we present the estimated percentage of agencies in categories which were selected from the more important questionnaire items. These estimates are weighted averages of the regional estimates, given in Appendix H, and their sampling errors are also listed. For most estimates, the standard errors are between 2 percent and 3 percent, giving us the following convenient rule of thumb: If P is the estimated percentage for the country P $\pm$ 5 percent is approximately the 95 percent confidence interval for most estimates.

In Table 2 we present the estimated (median) number* of persons in certain categories of interest and the standard error of estimate. Although these are national estimates, some estimates are based on small sample sizes. For example, of those agencies that gave their staff size, only a portion gave the breakdown of staff into categories listed in the questionnaire. In addition, some of the numbers being estimated are very small, often less than 1. This means that there are many zeros in the distributions of these numbers, which leads to imprecision in estimating statistics such as the median. Therefore, for example, the estimated number of DD staff is probably more unreliable than is indicated in the reported standard error.

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*We prefer to base our estimates of numbers on the median rather than the mean, because our sample of agencies is very heterogeneous. For example, our sample includes private agencies with less than 10 clients and state hospitals with over 2,000 clients. As is well known, the median is less sensitive than the mean to extreme values, and we believe that it is estimated with much more reliability than the mean (crude reliability estimates are presented in Table 2).

TABLE 1

ESTIMATED PERCENTAGE, AND STANDARD ERROR FOR SELECTED CATEGORIES OF AGENCIES

CATEGORY	Estimated Percent of Agencies That Are/Have	Standard Error
Private	51	2.0
Serving DD Longer than 10 Years	60	2.1
Federal Government as Largest Source of Income	27	1.7
Budget Under $100,000	39	2.3
Under 49,000 People in Catchment Area	31	2.0
Under 5 percent Minorities in Catchment Area	43	1.9
Located in Rural Area	50	2.0
Over 20 Paid Staff	29	1.9
Zero Minority Paid Staff	35	2.0
Over 50 Clients	56	2.4
Under 10 Minority Clients	61	2.7
Outreach Program	56	2.3
No Waiting List	64	2.3
Roundtrip of Under 10 miles for Typical Client	43	2.5
Need for Language Other than English	36	2.1
Policy Board	84	1.5
Under 10 Board Members, if They Have a Board	40	2.4
Zero Minority Board Members, if They Have a Board	52	2.5

TABLE 2

ESTIMATED NUMBER, AND STANDARD ERROR OF PAID STAFF PER AGENCY AND CLIENTS PER AGENCY

VARIABLE	Estimated Number	Standard Error
Paid Staff	15.1	0.5
Paid Minority Staff	3.0	0.5
Clients	63.6	7.9
Minority Clients	13.2	0.8
Board Members	13.7	0.6
Minority Board Members	2.3	0.3

With the exception of the estimated number of clients, the standard errors are about .5, giving us the following convenient rule of thumb: If X is the estimated number of persons in a particular category for the country as a whole (excepting the category "client, regardless of race"), then the true Number is very likely to lie in the range X $\pm$ 1. The true number of clients is very likely to be in the range X $\pm$ 16.

We now present the percentage distribution for each questionnaire item and some cross-tabulations for selected pairs and triples of variables. We present the entire percentage distribution, rather than a summary such as the median, because there is a paucity of data on the developmentally disabled, and future researchers will almost certainly need to know the range of responses as well as the typical or average response.

The data is grouped according to Objectives A to D stated on page 10.

Objective A: Structure and Demographic Characteristics of DD Agencies

Table 3 shows the percentage distributions for certain background agency variables, and the response percentage of agencies that give usable data. These background variables are agency type, number of years involved in DD service, proportion of disabled persons among its clientele, largest source of funding, annual budget, total population and minority percentage in the agency's catchment area, the type of area where the agency is located, and the size and structure of the agency's policy board and paid staff. The following description of this table does not address the possible correlations among these variables. Such correlational data will be presented in subsequent tables.

About half of DD agencies are private, and about 60 percent have been serving the developmentally disabled for more than 10 years. The commitment of an agency to the DD movement is reflected in the proportion of develop-

mentally disabled persons among the agency's clientele. We estimate that about half of DD agencies are primarily devoted to serving the disabled in the sense that at least 90 percent of their clients are developmentally disabled.

For the most part, agencies receive funds from public rather than privates sources, and about 40 percent of agencies have budgets under $100,000.

TABLE 3

PERCENTAGE DISTRIBUTIONS OF RESPONSES TO ITEMS ABOUT THE STRUCTURE AND DEMOGRAPHIC CHARACTERISTICS OF DD AGENCIES

VARIABLE/VALUE	Response Percentage	National Estimates
Type of Agency	99	
State government		25
Local government		17
Private non-profit		46
Private, profit		5
Other		7
Number of Years Serving DD	91	
Under 5 years		14
6 to 10 years		27
Over 10 years		60
Proportion of Clients Served Who have A Developmental Disability	85	
90 to 100%		49
11 to 89%		20
Under 11%		32
Largest Source of Income	97	
Federal government		27
State government		39
Local government		13
Foundations and other Private Groups		1
United Way and other Voluntary Fund-Raising Sources		7
Membership fees		0
Client fees		6
Other		7
Annual Budget for DD Services	80	
Under $100,000		40
$100,001 to $500,000		31
Over $500,000		29
Population in Catchment Area	90	
Under 49,000		29
49,001 to 100,000		17
100,001 to 500,000		27
Over 500,000		26
Proportion of Minority Population in Catchment Area	94	
Under 5%		36
6 to 10%		17
11 to 20%		15

Continues...

Table 3 cont'd.

Variable/Value	Response Percentage	National Estimates
Proportion of Minority Population in Catchment Area	94	
21 to 30%		13
Over 30%		19
Location of Agency	93	
Rural		49
Urban		29
Suburban		14
Reservation		0
Other		8
Have a Policy/Decision-Making Board	94	83
Number of Persons on Board	77	
1 to 5		14
6 to 10		25
11 to 20		38
Over 20		23
Number of DD Persons on Board	71	
Zero		79
1 to 5		12
Over 5		9
Number of Minority Persons on Board	71	
Zero		48
1 to 5		42
Over 5		10
Number of Paid Staff	93	
Zero		1
1 to 10		30
11 to 20		41
Over 20		28
Number of Minority Paid Staff	90	
Zero		36
1 to 10		44
11 to 20		15
Over 20		5

About as many agencies have highly populated (that is, over 500,000 people) as sparsely populated (that is, under 49,000) catchment areas, and about one-third of agencies have less than 5 percent minority persons in

their catchment areas. It can be seen in Appendix H that these percentage distributions show a marked variation across the 10 regions. As expected, regions with a larger total population tend to have agencies with more heavily populated catchment areas, and regions with a high percentage of minority persons tend to have agencies with a higher percentage of minorities in their catchment areas.

Concerning the location of agencies, about half of agencies are located in rural areas. The regional distributions shown in Appendix H show that agencies vary significantly by region in their locational setting. This variation corresponds closely with the regional variation in the percentage of people living in rural areas, according to the 1970 Census. Indeed, the correlation between the proportion of rural agencies and the proportion of rural residents across regions is as high as .70.

Over 80 percent of agencies have a policy or decision-making board, and the median number of board members is about fourteen. Finally, in Table 3, it can be seen that 40 percent of agencies employ between 11 and 20 people; and over a third of agencies employ no minority persons.

More information about the characteristics of board members and their method of selection are presented in Tables 4 and 5. The median number of minority persons on boards is about 2, and developmental disability representation on policy boards is about 3 percent. Nearly 40 percent of the board members are elected by other board members, just over 20 percent are appointed by public officials, and another 20 percent are elected by members.

As Table 6 shows, the median number of paid employees per agency is just over fifteen, about seven of whom are in direct service, and about three of whom are minority persons. The proportion of minorities is lowest in the administrative category and highest in the outreach category. About 4 percent of all workers have a developmental disability.

TABLE 4

ESTIMATED NUMBER (and percentage) OF POLICY BOARD MEMBERS PER AGENCY BY (i) ETHNICITY, AND (ii) DISABILITY STATUS

VARIABLE/VALUE	Disability Status		TOTAL
	DD	Non-DD	
Total Number on Board Per Agency	0.4	13.3	13.7
Number of Non-minorities on Board	0.3	11.1	11.4
Number of Minorities on Board	0.1	2.2	2.3
Percent Minorities	25	17	17
Percent DD on Board	3		

TABLE 5

ESTIMATED NUMBER (and percentage) OF POLICY BOARD MEMBERS PER AGENCY BY (i) METHOD OF SELECTION TO THE BOARD AND (ii) ETHNICITY

VARIABLE	METHOD OF SELECTION					TOTAL
	Elected by Community	Elected by Board Members	Appointed by Public Official	Elected by Member-ship	Other	
Total Number on Board	1.4	5.2	3.1	3.1	1.1	13.9
Number of Non-minority DD on Board	1.2	4.3	2.6	2.5	0.9	11.5
Number of Minori-ties on Board	0.2	0.9	0.5	0.6	0.2	2.4
Percent Minorities on Board	14	17	16	19	18	17

Links Among Background Variables

The foregoing tables (including Table 6 on next page) give the distributions for individual background agency variables. More information about the structure of agencies is obtained by examining the correlations among the variables already discussed. As suggested by our literature search and our meetings with those in the DD movement, the level and nature of DD services are strongly related to an agency's type and the size of its budget.

TABLE 6

ESTIMATED NUMBER (and percentage) OF PAID EMPLOYEES
PER AGENCY BY (i) CATEGORY OF EMPLOYMENT,
(ii) ETHNICITY AND (iii) DISABILITY STATUS

VARIABLE	CATEGORY OF EMPLOYMENT				TOTAL
	Administrative	Direct Service	Clerical	Outreach	
Total Number of Staff Per Agency	3.5	7.2	3.7	0.7	15.1
Number of Non-minority Staff Per Agency	3.1	5.4	3.1	0.5	12.1
Number of Minority Staff Per Agency	0.4	1.8	0.6	0.2	3.0
Percent Minorities	11	25	16	29	20
Number of DD Per Agency	0.1	0.3	0.1	0.03	0.5
Percent Developmentally Disabled	3	4	3	4	4

As Table 7 indicates, an agency's type is associated with how long the agency has been serving the DD, its geographical location, and the source of most of its funding. For example, state government agencies, relative to private agencies, have generally been serving the DD longer, and are more likely to be in a rural location, and list the Federal Government as their largest funding source. This last finding is as expected, since federal funds are channeled principally through state agencies.

TABLE 7

PERCENTAGE DISTRIBUTION OF NUMBER OF YEARS SERVING DD, LARGEST
SOURCE OF FUNDING, AND LOCATION OF AGENCY BY TYPE OF AGENCY
(The percentages in each row sum to 100)

TYPE OF AGENCY	Number of Years Serving DD		Largest Source of Funding		Location of Agency		
	Under 10	Over 10	Federal Government	Other	Rural	Urban	Other
State government	34	66	42	58	57	19	24
Local government	37	63	23	77	60	25	15
Private and Other	46	54	24	76	42	35	23

The data in Table 8 show that an agency's type is also associated with budget size and the demographic characteristics of its catchment area. For example, state agencies have larger budgets than private agencies or local government agencies, which is not surprising, since the Federal Government is a major source of funds, and channels most of these funds through state agencies. Nearly half the state agencies have budgets exceeding $500,000, whereas only about one-quarter of the other agencies have budgets that large.

Although there is no difference in the total number of people living in the catchment areas of state and private agencies, there is a greater percentage of minorities in the areas of state agencies compared to private and local government agencies. The percentage of minorities in the catchment areas of local government agencies is the lowest of all. Whereas only 26 percent of the state government agencies report less than 5 percent minorities in their area, 37 percent of the private agencies and 47 percent of the local government agencies report less than 5 percent in their areas respectively. (See Table 8).

TABLE 8

PERCENTAGE DISTRIBUTION OF BUDGET, TOTAL POPULATION IN CATCHMENT AREA (by thousands) AND PROPORTION OF MINORITIES IN CATCHMENT AREA BY TYPE OF AGENCY

TYPE OF AGENCY	BUDGET in '000			Total Population in Catchment Area			Proportion of Minorities in Catchment Area		
	Under $100	$100 - $500	Over $500	Under 49	49 - 100	Over 100	Under 5%	6 to 20%	Over 20%
State government	25	26	49	27	14	59	26	30	44
Local government	54	21	25	42	24	34	47	25	28
Private and Other	41	36	23	26	17	57	37	35	29

The proportion of disabled among the agency's clientele is associated with the agency's type, budget, and population in its catchment area. For

example, private agencies are more likely than public agencies to have the developmentally disabled as a client. Among those agencies with over 90 percent of their clientele who are disabled, only 30 percent are public, whereas of those with less than 10 percent of their clientele who are disabled, 55 percent are public.

Likewise, budget size is positively associated with DD service. Among agencies with over 90 percent developmentally disabled clients, 36 percent have budgets of over $500,000, whereas among agencies with less than 10 percent, only 10 percent have such large budgets. This positive correlation between budget size and clientele probably occurs because local government agencies tend to have small budgets and few clients who are developmentally disabled. Similarly, the association between a high proportion of clients who are disabled and a large total population in the catchment area probably occurs because there is a greater number of the developmentally disabled in the area (see Table 9).

TABLE 9

PERCENTAGE DISTRIBUTION OF TYPE OF AGENCY, TOTAL POPULATION IN CATCHMENT AREA, AND BUDGET (by thousands) BY PROPORTION OF AGENCY'S CLIENTS WHO ARE DEVELOPMENTALLY DISABLED

PROPORTION OF CLIENTS WHO ARE DEVELOPMENTALLY DISABLED	TYPE OF AGENCY			Total Population in Catchment Area in '000			BUDGET in '000		
	State Government	Local Government	Private and Other	Under 49	49 - 100	Over 100	Under $100	$100 $500	Over 500
90 to 100%	22	8	69	24	18	58	27	37	36
11 to 89%	30	16	54	22	20	58	33	33	34
0 to 10%	24	31	45	39	17	44	68	20	12

Not only is an agency's location related to its type (public agencies tend to be in rural areas), but location is related to the size of the area's minority population and the number of minority group members served. More

specifically, as indicated by Table 10, urban catchment areas contain the highest percentages of minorities, as might be expected, since the Census data shows that minorities are more likely to live in urban areas. In turn, these urban agencies have a higher proportion of minorities who are developmentally disabled.

TABLE 10

PERCENTAGE DISTRIBUTION OF MINORITY PROPORTION IN CATCHMENT AREA BY LOCATION OF AGENCY

LOCATION OF AGENCY	Proportion of Minorities in Catchment Area of Agency		
	Under 5%	6 to 20%	Over 20%
Rural	53	23	24
Urban	17	35	48
Suburban and Other	23	47	30

The size of an agency's staff is not associated with agency type, although it is positively correlated, as expected, with the agency's budget size and the total population of the catchment area. Among agencies with fewer than 10 paid employees, over 75 percent have budgets under $100,000 and 42 percent have catchment area populations under 49,000. Correspondingly, among agencies with over 50 paid employees, only 17 percent and 13 percent respectively have such low budgets or small area populations. Small agencies (with fewer than 10 employees) are also more likely than large agencies to be located in a rural area. (See Table 11),

As expected, the size of an agency's minority staff is positively correlated with the proportion of minorities in the catchment area and the agency's location. (See Table 12). This is the case, since minority representation is higher in urban areas. Agencies with no minority staff are most likely to be located in rural areas, whereas agencies with over 10

minority staffers are most likely to be located in urban areas.

TABLE 11

PERCENTAGE DISTRIBUTION OF BUDGET, TOTAL POPULATION IN CATCHMENT AREA (by thousands) AND LOCATION OF AGENCY BY SIZE OF PAID STAFF

SIZE OF PAID STAFF	BUDGET in '000			Total Population in Catchment Area			LOCATION OF AGENCY		
	Under $100	$100 - $500	Over $500	Under 49	49 - 500	Over 100	Rural	Urban	Suburban and Other
Under 10	76	18	6	42	19	39	53	29	18
11 to 50	27	54	19	31	19	50	53	28	19
Over 50	17	13	70	13	13	74	41	31	28

TABLE 12

PERCENTAGE DISTRIBUTION OF MINORITY PROPORTION IN CATCHMENT AREA AND LOCATION OF AGENCY BY SIZE OF MINORITY STAFF

SIZE OF MINORITY STAFF	Proportion of Minorities in Catchment Area			Location of Agency		
	Under 5%	6 to 20%	Over 20%	Rural	Urban	Suburban and Other
Zero	62	26	12	66	19	15
1 to 10	29	37	34	47	31	22
Over 10	7	31	62	27	44	29

Objective B: Extent and Nature of Services Provided by Agencies

In Table 13 we present data about the services offered by agencies. About 40 percent of agencies have an in-service training program for staff on minority cultures and values. Among agencies with no such program, the reasons most often given for not having the program are that there are no minorities in the agency's service area, and that the cost of such a program is not included in the agency's budget.

TABLE 13

PERCENTAGE DISTRIBUTIONS OF RESPONSES TO ITEMS ABOUT THE EXTENT AND NATURE OF SERVICES PROVIDED BY DD AGENCIES

VARIABLE/VALUE	Response Percentage	National Estimates
Have in-service training for staff on culture etc. of minority groups	85	37
If no in-service training reasons are	52	
No minority in service area		24
Not necessary -- all minority staff		1
Cost of program not in budget		26
Other		49
Methods used to recruit paid staff		
Word of mouth		
White	83	32
Minority	82	29
Other agencies		
White	83	24
Minority	82	21
Professional journals		
White	83	13
Minority	82	11
Civil Service		
White	83	24
Minority	82	23
Newspaper, radio, TV		
White	83	48
Minority	82	45
Employment agency		
White	83	25
Minority	82	23
Agency staff recommendations		
White	83	22
Minority	82	20

Continues...

Table 13 cont'd.

Variable/Value	Response Percentage	National Estimates
Community Persons or groups		
White	83	21
Minority	82	22
Method of referral for largest number of minority clients	80	
Self referral		14
Family referral		9
Medical referral		9
Non-medical professional referral		6
Other agency referral		32
Case-finding and outreach		8
School referral		13
Court referral		1
Other		10
Method of referral for largest number of non-minority clients	84	
Self referral		16
Family referral		11
Medical referral		12
Non-medical professional referral		6
Other agency referral		28
Case-finding and outreach		6
School referral		12
Court referral		1
Other		8
Most frequently provided service for DD clients	96	
Identification		21
Direct services		15
Treatment		9
Education		27
Residential services		9
Employment		10
Family/Program support		3
Outreach		0
Other		7
Have outreach program	85	57
Purpose of outreach program	49	

Continues...

Table 13 cont'd.

Variable/Value	Response Percentage	National Estimates
Referral of clients for services		10
Locating potential clients		16
Distribution of information		6
Community education and prevention		5
All of the above		53
Other		10
Methods used to reach DD clients in outreach programs		
Health fairs		
Whites	51	14
Minorities	50	14
Leaflet distribution		
Whites	51	39
Minorities	50	38
Parent groups		
Whites	51	28
Minorities	50	27
Posters		
Whites	51	16
Minorities	50	15
Home visits		
Whites	51	35
Minorities	50	34
Visits to other agencies		
Whites	51	49
Minorities	50	49
Circulating mobile units		
Whites	51	2
Minorities	50	2
Radio, TV spots		
Whites	51	23
Minorities	50	23
Community meetings		
Whites	51	33
Minorities	50	32
Other		
Whites	51	14
Minorities	50	14

Continues...

Table 13 cont'd.

Variable/Value	Response Percentage	National Estimates
Reasons for not having an outreach program	36	
Not budgeted		22
Too costly		6
Not sufficiently staffed		14
Waiting list already too long		6
Not needed, community already aware of services		45
Area to be served is too large		3
Did not think about it		2
Do not know how to set it up		1
Minority populations know about and use services to fullest extent possible	81	74
Factors preventing minority populations from knowing about and using services		
Language barrier	24	31
Lack of transportation	24	36
Lack of information about agency	24	63
Families too involved in "survival issues"	24	45
Lack of communication between staff and parents	24	8
Agency hours do not meet clients' needs	24	8
Cannot afford to pay agency fees	24	6
Other	24	31
Eligibility requirements		
Income	83	20
Type of disability	84	52
Geographic location	84	39
Age	84	41
Sex	84	4
Marital status	84	3
Ethnic group	84	1
All of the above	84	2
No requirements	84	23
Time typically spent by client on waiting list	81	
No waiting list		63
1 to 2 months		22
Over 2 months		15

Continues...

Table 13 cont'd.

Variable/Value	Response Percentage	National Estimates
Round trip distance typically travelled by client	76	
Less than 10 miles		42
11 to 30 miles		41
Over 30 miles		17
Language other than English needed	85	36
Languages needed		
Sign Language	34	52
Spanish	34	60
Japanese	34	4
Chinese	34	7
Other	34	26
Languages other than English spoken by staff		
None, English only	84	52
Spanish	84	36
Japanese	84	5
Chinese	84	7
Other	84	28
Materials about agency are printed in language other than English	86	31
Language other than English used in material		
Spanish	29	85
Japanese	29	5
Chinese	28	4
Braille	28	10
Other	29	11

Overall, agencies list the following as eligibility requirements in order of frequency: type of disability, age, geographic location, and income. Normally, agencies do not list sex, ethnic group, or marital status as eligibility requirements, and about a quarter of the agencies have no requirements.

The methods used by agencies to recruit staff are about the same for minorities and non-minorities. In general, agencies rely most on the media -- newspapers, radio, and TV -- and next on "word of mouth." The least used method is professional journals.

The referral methods used to direct most clients to a given agency are the same for minorities and non-minorities. Most frequently, clients come from other agencies, and this method is followed by self-referrals. The most frequently provided service is "education," and the next most frequently provided service is "identification."

Nearly 60 percent of agencies have a DD outreach program, and the aims of these programs are listed as client referral, locating potential clients, distributing information, and community education and prevention. Generally, the agencies use similar methods to provide outreach to clients of all ethnic groups in all regions. Their most common method is making visits to other agencies, followed by leaflet distribution and home visits. Agencies that don't have an outreach program generally feel that the community is already aware of the services.

About three-quarters of the agencies report that minority populations know about and use their services to the fullest extent possible. When minorities do not make full use of services, agencies claim the main reason they do not do so is a lack of information about the agency. The next most important reason, according to these agencies, is that minority families are too involved in survival issues. The third listed reason is that they lack adequate transportation. On the whole, agencies don't see the inability of minorities to pay agency fees as an important factor preventing the use of services.

Most clients do not spend time on a waiting list, although about 20 percent have to wait from one to two months. Overall, about 40 percent of the clients travel less than 10 miles round trip to the agency, and another 40 percent travel from 11 to 30 miles.

Although about 52 percent of the agency staffers speak English only, another 36 percent speak Spanish. However, as can be seen in Appendix H, there is much regional variation, as might be expected. For example, in Region IX, a higher proportion of the agencies than elsewhere have staffers who speak Spanish, Japanese, and Chinese, which reflects the higher concentration of such peoples in this region. The agencies in this region are also more apt to issue materials in these languages than in other areas. Of those agencies that have materials printed in languages other than English, 85 percent have materials printed in Spanish and about 10 percent issue material in Braille.

In Table 14 we present information about the impact made by different categories of agency personnel on planning, policy formation and decision-making.

TABLE 14

PERCENTAGE DISTRIBUTIONS OF LEVEL OF IMPACT ON PLANNING, BY CATEGORY OF AGENCY PERSONNEL

IMPACT ON PLANNING	Category of Agency Personnel			
	Board Members	Direct Service Staff	Administrative Staff	Volunteer Staff
Great Deal	73	50	85	8
Some	21	48	14	48
None	5	2	1	44

Generally, agencies view the administrative staff as having the most impact on planning, policy formation, and decision-making, followed by board members and direct service staff. Volunteer staff members have very

little impact. More specifically, about 85 percent of the agencies feel the administrative staff has a great impact; 73 percent feel board members do; and 50 percent feel the service staff does. Only 8 percent feel volunteer staff has a great impact.

Links Between Outreach Activity and Background Agency Variables.

In Table 15 we present data on the relationship between availability of outreach program and certain background variables. For example, agencies with an outreach program are more likely than agencies without outreach programs to (i) have been serving the developmentally disabled for under 10 years, (ii) list the Federal government as their major funding source, and (iii) have a larger budget that is over $500,000.

Since outreach programs cost money, it is clear why agencies with these programs tend to have larger budgets and are more likely to obtain Federal funding. Also, it may be that the agencies serving the disabled for less time may be more likely to have an outreach program, since this is a way of recruiting new clients. Older agencies may be more established and have less need for such outreach.

TABLE 15

PERCENTAGE DISTRIBUTION OF NUMBER OF YEARS SERVING DD, LARGEST SOURCE OF FUNDING AND BUDGET (by thousands) BY WHETHER OR NOT AGENCIES HAVE AN OUTREACH PROGRAM

OUTREACH PROGRAM	Number of Years Serving DD		Largest Source of Funding		Budget in '000		
	Under 10	Over 10	Federal	Other	Under $100	$100 - $500	Over $500
Yes	46	54	33	67	37	29	34
No	36	64	23	77	42	34	24

Objective C: Characteristics of Clientele

As shown in Table 16, the typical agency has about 64 clients, about 13 of whom are minority group members. (Estimates are medians, as shown in Tables 2, 4, 5, and 6.) The great majority of clients (about 70 percent) are mentally retarded.

TABLE 16

ESTIMATED NUMBER (and percentage) OF CLIENTS PER AGENCY BY (i) TYPE OF DISABILITY, AND (ii) ETHNICITY

VARIABLE	TYPE OF DISABILITY						
	Autism	Cerebral Palsy	Epilepsy	Mental Retardation	Multiple Diagnosis	Other	TOTAL
Total Number of Clients Per Agency	1.5	4.2	3.7	44.3	9.9	0	63.6
Percentage	2	7	6	70	15	0	100
Number of Non-Minority Clients Per Agency	1.0	3.1	2.6	36.6	7.1	0	50.4
Number of Minority Clients Per Agency	0.5	1.1	1.1	7.7	2.8	0	13.2

In Table 17 we present the percentage distribution for the total number of clients, the number of clients with specific disabilities, the number of minority clients, and the age of clients. Only 14 percent of the agencies reported no mentally retarded clients, whereas 74 percent reported no autistic clients, 52 percent no cerebral palsied clients, 56 percent no epileptic clients, and 36 percent no multiple diagnosis clients. Overall, about 23

percent* of clients are minority persons, a percentage that varies across regions in parallel with the percentage of minorities living in the region.

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* The estimate derived from Table 16 would be (13.2/63.6)100 = 21%. This discrepancy is due to the fact that 13.2 is the total of estimates for each type of disability. Since each of these estimates has some error of measurement, the total obtained through aggregation is much more unreliable than the median of the overall distribution of minority clients. This latter median is 14.6 which is 23% of 63.3.

TABLE 17

PERCENTAGE DISTRIBUTIONS OF RESPONSES TO ITEMS ABOUT THE AGE OF CLIENTS AND THEIR SPECIFIC DISABILITIES

VARIABLE/VALUE	Response Percentage	National Estimates
Age of largest group of DD clients served	88	
0 to 1 year		2
2 to 4 years		11
5 to 9 years		11
10 to 14 years		10
15 to 19 years		9
20 to 64 years		56
Over 65 years		2
Number of DD clients	80	
Under 10		14
11 to 50		31
51 to 100		15
101 to 200		13
201 to 500		14
Over 500		14
Number of autistic clients	70	
Zero		73
1 to 10		21
11 to 50		4
51 to 100		1
Over 100		0
Number of cerebral palsy clients	69	
Zero		52
1 to 10		32
11 to 50		9
51 to 100		3
Over 100		5
Number of epileptic clients	69	
Zero		56
1 to 10		30
11 to 50		8
51 to 100		3
Over 100		3

Continues...

Table 17 cont'd.

VARIABLE/VALUE	Response Percentage	National Estimates
Number of Mentally retarded clientele	69	
Zero		14
1 to 10		21
11 to 50		29
51 to 100		11
Over 100		26
Number of multiple diagnosis clientele	69	
Zero		36
1 to 10		27
11 to 50		20
51 to 100		6
Over 100		10
Number of minority DD clients	66	
Zero		25
1 to 10		33
11 to 50		23
51 to 100		7
Over 100		12

Most clients tend to be over 20 years old. About 60 percent of agencies state that their typical client is in this age bracket.

Table 18 contains the percentage distributions of the number of clients and of minority clients living in various settings. It can be seen that less than 30 percent of the clients live outside of their homes in an institution, in an out-of-home community placement, or in other out-of-home settings.

TABLE 18

PERCENTAGE DISTRIBUTIONS OF RESPONSES TO ITEMS
ABOUT THE SETTINGS IN WHICH CLIENTS LIVE

VARIABLE/VALUE	Response Percentage	National Estimates
Number of clients living in own home	69	
Zero		18
1 to 10		14
11 to 50		30
51 to 100		12
Over 100		26
Number of minority clients living in own home	61	
Zero		45
1 to 10		26
Over 10		29
Number of clients living in institutions	69	
Zero		66
1 to 10		13
Over 10		21
Number of minority clients living in institutions	64	
Zero		81
1 to 10		11
Over 10		9
Number of clients living in out of home community placement	69	
Zero		41
1 to 10		21
Over 10		39
Number of minority clients living in out of home community placement	63	
Zero		69
1 to 10		23
Over 10		9

Table 19 contains data about client involvement in the planning and implementation of services. The most frequently listed way in which clients are involved is in making suggestions and informing the agencies of their needs through their case worker. There is a small amount of participation in committee work and in parent-social-worker meetings, but there is almost no parent involvement in outreach activities, fund raising, or as members of advocacy groups.

TABLE 19

PERCENTAGE DISTRIBUTIONS OF RESPONSES TO ITEMS ABOUT CLIENT INVOLVEMENT IN THE PLANNING AND IMPLEMENTATION OF SERVICES

VARIABLE/VALUE	Response Percentage	National Estimates
Ways in which largest number of clients participate in implementation and delivery of agency programs and services	79	
Outreach activities		4
Serve on committees, etc.		14
Inform agency of their needs through their worker		40
Agency volunteer		3
Seek or contribute funds		1
Not involved		26
Other		13
Ways in which largest number of clients participate in planning of agency programs and services	80	
Serve on committee		12
Participate in parent-social worker meetings		14
Member of advocacy group		5
Suggestions made through case worker		29
Not involved		25
Other		15

Links Between Client Characteristics and Background Agency Variables.

As Table 20 indicates, state government agencies (which have the

largest budget size) have the largest clientele, and private agencies the smallest. However, since there are many more private agencies, most clients (54 percent) are served by these, even though individually, state agencies serve more clients.[1]

TABLE 20

ESTIMATED NUMBER (and percentage) OF CLIENTS PER AGENCY
BY (i) TYPE OF AGENCY, AND (ii) ETHNICITY
(To aid interpretation, the percentage of distribution by type of agency is given in the first row.)

VARIABLE	TYPE OF AGENCY		
	State Government	Local Government	Private and Other
Percent Agencies	25	17	58
Total Number of clients Per Agency	73.9	65.4	58.7
Number of Non-minority Clients Per Agency	56.8	53.4	46.9
Number of Minority Clients Per Agency	17.1	12.0	11.8
Percent Minority Clients	23	18	20

[1] This can be determined through simple calculations with the data in Table 20. If we randomly select 100 agencies, about 25, 17, and 58 of these would be state government, local government, and private or other agencies, respectively. Based on the average number of clients served, each type of agency would serve the following number of clients: The state government agencies would serve 25 x 73.9 = 1848 clients; the local government ones 17 x 65.4 = 1112 clients; and the private agencies 58 x 58.8 = 3410 clients. The total number of clients served by these 100 agencies is 6370 ($\approx$ 63.6 x 100), as expected.

Other variables associated with size of clientele are included in Table 21. The association with type of agency is consistent with the data shown in the previous Table. The positive correlations with budget size and with total population in the catchment area are analogous to the positive correlations between these two variables and size of paid staff (see Table 11). Finally from Table 21, it can be seen that there is a tendency for agencies with fewer than 50 clients to be located in rural areas to a greater degree than agencies with over 50 clients. This finding is analogous to the association between location and size of staff.

TABLE 21

PERCENTAGE DISTRIBUTION OF TYPE OF AGENCY, BUDGET, TOTAL POPULATION IN CATCHMENT AREA AND LOCATION OF AGENCY BY SIZE OF CLIENTELE

SIZE OF CLIENTELE	TYPE OF AGENCY			BUDGET in '000			TOTAL POPULATION IN CATCHMENT AREA '000		
	State Government	Local Government	Private and Other	Under $100	$100-$500	Over $500	Under 49	49-100	Over 100
Under 50	18	18	64	60	31	9	45	17	38
Over 50	26	15	59	19	37	44	16	21	63

Table 21 cont'd.

SIZE OF CLIENTELE	LOCATION OF AGENCY		
	Rural	Urban	Suburban and Other
Under 50	58	28	14
Over 50	45	30	25

As previously noted, the agencies' most frequently provided service is education, and this holds true for agencies of different type and budget size. However, there is a relationship between client age and budget size. As Table 22 indicates, about 50 percent of the agencies that cater to clients under 20 years old have budgets under $100,000, whereas only about 30% of

the agencies catering to clients over 20 have such budgets. Conversely, agencies catering to clients over 20 have larger budgets.

TABLE 22

PERCENTAGE DISTRIBUTION OF BUDGET BY
TYPICAL AGE OF CLIENTS
(by thousands)

TYPICAL AGE OF CLIENTS	BUDGET in '000		
	Under $100	$100-$500	Over $500
Under 20 years	52	29	19
Over 20 years	29	35	36

An issue of some importance is the cost-effectiveness of the various types of agencies. A detailed treatment of this issue is beyond the scope of this survey, but some of the data collected are relevant. One aspect of the issue is the relation between size of clientele, regarded as an output of an agency, and size of budget and of paid staff, regarded as inputs to the agency. One measure of cost-effectiveness is the extra output generated by each additional unit of input. As an index of size of clientele we can use the percentage of "large" agencies (i.e., agencies with over 50 clients) for each type of agency. In Figure 9 we show the relationship between this output index and each input, separately for each type of agency. Cost-effectiveness is then measured by the overall slope of each curve. It can be seen that, in both graphs, the slope of the curve is greatest for private agencies, suggesting that these agencies are more cost-effective than the other types of agencies. It has to be stressed that firm conclusions on this matter should await a more comprehensive survey and analysis.

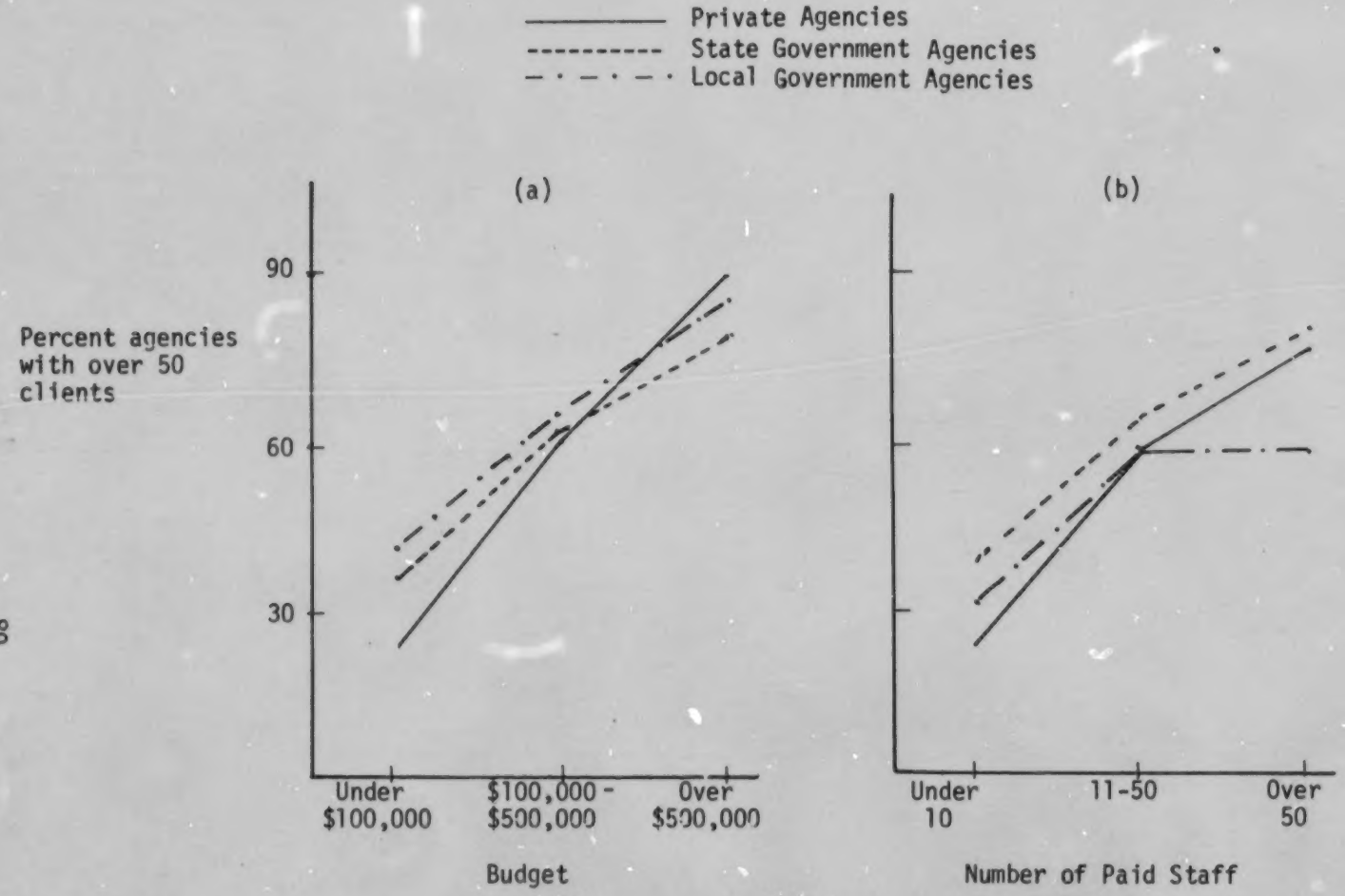

Figure 9: Relations between size of clientele (output) and (a) Budget and (b) Size of staff (input factors) for each of three types of agency. (Size of clientele is indexed by percentage of agencies having more than 50 clients.)

Objective D: Level of Minority Participation and Related Variables

We have already reported that minority persons comprise about 17 percent of agency board members (see Table 4), about 20 percent of the staff (see Table 6), and about 21 percent of the clients (see Table 16). The size of the minority clientele per agency is related to a number of variables in ways that are not unexpected. It can be seen from Table 23 that the variables, agency type, budget size, total population in catchment area and agency location, which are associated with size of total clientele (see Table 21), are also associated with size of minority clientele. This is to be expected because of an approximate proportionality between the number of minority clients and the total number of clients. In addition to these relationships, size of minority clientele is positively correlated with proportion of minorities in the catchment area. This correlation doubtless occurs for the same reason as that between size of minority staff and proportion of minorities, namely, that minority participation in agencies is related to the availability (proportion) of minority persons in the catchment area.

TABLE 23

PERCENTAGE DISTRIBUTION OF TYPE OF AGENCY, BUDGET, TOTAL POPULATION IN CATCHMENT AREA, MINORITY PROPORTION IN CATCHMENT AREA, AND LOCATION OF AGENCY BY SIZE OF MINORITY CLIENTELE

SIZE OF MINORITY CLIENTELE	TYPE OF AGENCY			BUDGET IN '000			TOTAL POPULATION IN CATCHMENT AREA IN '000		
	State Government	Local Government	Private and Other	Under $100	$100-$500	Over $500	Under 49	49-100	Over 100
Zero	14	22	64	60	31	9	48	24	28
1-10	16	12	72	41	38	21	36	18	46
over 10	28	15	57	21	36	43	15	19	66

Continues...

Table 23 cont'd.

SIZE OF MINORITY CLIENTELE	PROPORTION OF MINORITIES IN CATCHMENT AREA			LOCATION OF AGENCY		
	Under 5%	6-20%	Over 20%	Rural	Urban	Suburban and Other
Zero	70	26	4	73	17	10
1 - 10	44	34	22	53	30	17
over 10	15	33	52	43	35	22

Meetings conducted with workers in the DD field suggest that there is a relationship between the number of minority clients and (i) whether agencies try systematically to recruit minorities through, for example, outreach programs, and (ii) the number of minority staff persons. The distributions in Table 24 show that agencies that use some method to reach minorities in their outreach program have more minority clients than agencies that use no such method. This is so whether we restrict our attention to "small" agencies (i.e., those with under 50 clients in all) or to "large" agencies.

TABLE 24

PERCENTAGE DISTRIBUTION OF SIZE OF MINORITY CLIENTELE PER AGENCY BY WHETHER OR NOT AGENCIES USE SOME METHOD TO REACH MINORITIES IN OUTREACH PROGRAM. The Distribution is Shown for (a) Agencies With Fewer Than 50 Clients, and (b) Agencies With More Than 50 Clients

SIZE OF CLIENTELE	Any of presented methods used to reach minorities?	Number of Minority Clients Per Agency		
		Zero	1 - 10	Over 10
(a) Under 50	Yes	31	51	18
	No	48	39	13
(b) Over 50	Yes	7	18	74
	No	19	25	56

The distributions in Tables 25 and 26 show that, as expected, there is a positive correlation between size of minority staff and size of minority clientele. To reduce the chance that this correlation is entirely spurious, we present the relationship separately for agencies with low, medium and high minority proportions in their catchment areas (Table 25), and separately for agencies with less than 50, and more than 50 clients (Table 26).

Finally, it can be seen in Table 27 that the size of minority clientele is associated with the most frequently provided service, and that the nature of the association depends on the size of the total clientele. Among "small" agencies, those agencies that provide mainly education for clients tend to have the greatest numbers of minority clients. On the other hand, among "large" agencies, those agencies that provide mainly identification for clients tend to have the greatest numbers of minority clients.

TABLE 25

PERCENTAGE DISTRIBUTION OF SIZE OF MINORITY CLIENTELE PER AGENCY BY SIZE OF MINORITY STAFF, CONTROLLING FOR PROPORTION OF MINORITIES IN CATCHMENT AREA

Proportion of Minorities in Catchment Area	Size of Minority Staff	Size of Minority Clientele		
		Zero	1 - 10	Over 10
Under 5%	0	55	37	8
	1 - 10	39	38	23
	Over 10	0	25	75
6 - 20%	0	39	32	29
	1 - 10	14	44	42
	Over 10	7	22	70
Over 20%	0	6	33	61
	1 - 10	3	26	71
	Over 10	4	17	79

TABLE 26

PERCENTAGE DISTRIBUTION OF SIZE OF MINORITY CLIENTELE
PER AGENCY BY SIZE OF MINORITY STAFF, CONTROLLING FOR SIZE OF TOTAL CLIENTELE

TOTAL NUMBER OF CLIENTS PER AGENCY	Size of Minority Staff	Size of Minority Clientele		
		Zero	1 - 10	Over 10
Under 50	0	58	39	3
	1 - 10	24	51	25
	Over 10	15	52	33
Over 50	0	26	30	44
	1 - 10	12	25	63
	Over 10	0	7	93

TABLE 27

PERCENTAGE DISTRIBUTION OF SIZE OF MINORITY CLIENTELE PER AGENCY BY
MOST FREQUENTLY PROVIDED SERVICE, CONTROLLING FOR SIZE OF TOTAL CLIENTELE

TOTAL NUMBER OF CLIENTS PER AGENCY	Most Frequently Provided Service	Size of Minority Clientele		
		Zero	1 - 10	Over 10
Under 50	Identification	45	48	7
	Direct Service	39	42	19
	Education	29	46	25
	Other	50	46	4
Over 50	Identification	2	16	82
	Direct Service	15	16	69
	Education	10	25	65
	Other	19	24	56

Finally, it can be seen in Table 28 that size of minority clientele is positively correlated with number of minority persons on the board. This result holds for "small" agencies and for "large" agencies.

TABLE 28

PERCENTAGE DISTRIBUTION OF SIZE OF MINORITY CLIENTELE PER AGENCY BY NUMBER OF MINORITY PERSONS ON POLICY BOARD, CONTROLLING FOR SIZE OF TOTAL CLIENTELE

Total Number of Clients Per Agency	Number of Minority Persons on Board	Size of Minority Clientele		
		Zero	1 - 10	Over 10
Under 50	0	50	45	5
	1 or more	21	53	26
Over 50	0	23	30	47
	1 or more	4	15	81

Objective E: Unmet Needs of the Minority Developmentally Disabled

A frequently mentioned perception at our meetings was that the needs of minority persons are different from those of non-minority persons who are developmentally disabled. Several studies discuss this perception although they do so in rather vague terms. The agencies in our survey were asked in an open-ended format, to identify and comment on the unmet service needs of the minority population as a separate group. While not all respondents chose to comment, the majority of those who did challenged this perception. Comments, such as "...the developmental needs of individual clients are more important than race," and "...the needs of minority and non-minority persons are the same, that is, the need to be accepted, to be reasonably accomodated and given opportunity, and the need to be gainful, productive citizens," were frequently made.

However, a number of agencies did list their perception of the unmet needs of minority clients. Some agencies felt that these needs were due to inadequacies within the service delivery system, centering around what they

interpreted as the failure of the system to bring the minority consumer and the minority professional into the mainstream of the DD movement. One typical comment was; "...lack of national, state and local efforts to relate to problems of minorities which prevent them from seeking services, that is, lack of identity with national causes: United Cerebral Palsy, National Association for Retarded Citizens, etc. This leads to organizational isolation of the minority developmentally disabled and lack of historical involvement with the movement." Some agencies felt they needed to do more outreach and to develop ethnically based materials and information. Others stated the need to assist minority communities in being less defensive and apprehensive about coming forth to seek services. One comment in this regard was "... families need to be helped to acknowledge the existence of the disability and the need for remediation." Also the educational system was singled out as needing change. Some responses expressed the belief that the placement of minority children in EMR classes was indicative of the fact that the system is not meeting the need of those students.

Some agencies tended to lay the blame for low levels of minority participation on the minority community itself. One respondent felt that the minority community could do more in terms of using certain resources. It was stated that physicians are not effectively utilized and that this results in families not seeking treatment for the disability early enough. Some unmet needs appear to result from the inaccessibility of resources to minority communities and families, in particular, those services needed by persons with cerebral palsy. Finally, low-income was identified as a contributing factor to unmet needs.

SUMMARY OF LINKS AMONG VARIABLES

The following major points emerge from our analysis of the survey data.

- The typical agency has about 15 paid employees and 64 clients, and in both groups about 20 percent are minority persons.
- There are positive correlations among budget size, number of paid staff, and number of clients, making it unambiguous to refer to an agency as large or small depending on whether some or all of these three variables are large or small.
- The size of an agency is linked to other background agency variables, and to the nature of its services:
    - State government agencies are larger than local government and private and other agencies.
    - Larger agencies serve catchment areas with larger total populations.
    - Agencies located in urban and suburban areas are generally larger than those in rural areas.
    - The larger urban agencies are more likely to serve proportionately more minority clients, since more minority groups live in these areas.
    - Larger agencies with larger budgets are more likely to have an outreach program.
- State Government agencies are more likely than private and other agencies to have been serving the DD for over 10 years, list the Federal government as their largest source of funding, are located in rural areas, and are in areas with a high proportion of minority persons.

Minority participation in agency activities is linked to background agency variables and to the nature of the services offered by the agency:

- Both the proportion of minority staff and minority clients increases with the proportion of minority persons in the agency's catchment area.
- The number of minority clients, like the total number of clients served, increases with agency size, and is greater at public, and particularly state agencies.
- Agencies that seek to reach minorities through outreach programs have more minority clients than agencies that use no such method.
- The size of the minority clientele increases for small agencies providing mainly education and for large agencies providing mainly identification.
- The size of the minority clientele increases with the proportion of minority staffers and board members.

Concerning policy making boards, the following were observed:

- State agencies are much less likely to have policy making boards than other types of agencies
- Approximately 3 percent of the board members are developmentally disabled and about 17 percent are minority persons.
- Nearly 40 percent of the board members are recommended by other board members.

COMMENTS ON ANALYTIC METHODS

In assessing the relationships among variables, we have relied solely on the use of two and three-way cross tabulations. We did not apply multiple regression methods for the following reasons:

(1) As the cross-tabulations show, there is a high degree of inter-correlation among the background agency variables. Therefore, the use of these variables as simultaneous predictors of, for example, participation levels, would be beset with problems of multi-collinearity. Because of these problems, it would be difficult, if not impossible, to assess the relative importance of the various predictor variables.

(2) Because respondents did not provide usable responses for every item, the number of agencies that responded to all the items referred to in a multiple regression equation could be much less than the total number (732) of questionnaires that were analyzed. This reduction of effective sample size would reduce the reliability of the estimated regression weights.

(3) A third reason for preferring the non-parametric chi-square test over the parametric multiple regression method is that the stringent assumptions (of normality, etc.), on which the latter method is based, are almost certainly violated in our data.

(4) Because of these three considerations, we concluded that the use of multiple regression methods would not add an appreciable amount to our current understanding of the DD movement.

Limitations of Survey

Certain limitations of the study ought to be borne in mind as one tries to interpret and generalize the above findings:

1. Despite our intensive follow-up efforts, the response rate of agencies to our questionnaire was about 50%. This means that our data will be biased if there are appreciable differences between respondents and non-respondents. We have no way at present of estimating this bias because we did not conduct a follow-up study of non-respondents.

2. There is considerable variation in the record-keeping systems of agencies contacted. In some cases, agencies did not keep certain data or make the breakdowns sought in the questionnaire and, as a result, were unable to fill in all items.
3. In the present study, there is not systematic input from disabled persons who are not served by any agency. Thus, an important set of data on minority participation in the DD movement is missing from our account.

Due to these limitations, the present study should be regarded as only a partial attack on the problem of assessing the state of the art in the DD movement and minority participation in it. However, since this is a field where data is solely lacking, the data we have gathered should be helpful in furthering understanding of minority participation in the DD field. In addition, since the survey includes data on the non-minority disabled, it should increase understanding of the DD field generally.

This section has provided a summary of the major findings about minority participation in the DD movement and the agencies serving the disabled.

The following sections present the procedures and key findings of the study.

VII: DISCUSSION OF KEY FINDINGS

This section discusses the significance of the major survey findings, based on the overall responses of agencies throughout the country serving various ethnic groups, and considers the relationship between these findings and the views of individual service providers and consumers at the nationwide meetings.

From this survey, it would appear that minority persons are neither under-represented nor over-represented in the DD movement, since their participation as agency clients, employees, and board members is approximately at the same level as their proportion in the population as a whole. For example, minorities account for about 17 percent of the nation's population, 23 percent of agency clients, 20 percent of their employees, and 17 percent of their board members. However, we need to know the proportion of the minority population who are developmentally disabled before we are able to make a true comparison. Furthermore, when the data is examined more closely, it is apparent that minorities are not fully represented in the highest categories of employment -- administration -- although they are over-represented among the outreach category.

There are also some gaps in the data with respect to minorities of different ethnic groups. This is an important gap, since minorities of different groups may have different levels of participation. Accordingly, we need to know the DD prevalence rates separately for each ethnic group. However, since these figures are presently unknown and any estimates are unreliable, no firm conclusions can be reached about the level of minority participation in DD services.

The present study is not helpful in providing such data, since our sample sizes become very small when data are broken down by ethnic group, and so any estimates based on these samples are unreliable. Also, only certain agencies gave ethnic breakdowns of staff and clientele, and there may be some bias arising out of the characteristics of those agencies. For example, those agencies with a high percentage of minorities among staff and clientele may be more likely to break down their data by ethnic group and provide such data than agencies with lower minority percentages.

In short, the prevailing view expressed at our nationwide meetings that minorities are under-represented in the DD movement is not contra-indicated by our survey data. These data were obtained solely from agencies which collect such data, and are not detailed enough to allow for direct comparisons. More research is needed to find out some specific questions about minority participation. For example, are minority autistic children treated by agencies as frequently as non-minority autistic children? Or are American Indians who are dvelopmentally disabled served as frequently as Spanish Americans or Whites who are similarly disabled.

Our findings also suggest that whether an agency is public or private is an important factor in the nature of service provided to the disabled. At our meetings, participants expressed the view that public agencies are the prime providers of services to minority clients, and our survey supported this view. As we found, public and particularly state agencies tend to have larger budgets than private agencies, serve more clients, and be located in areas where minority persons live. However, since there are fewer public agencies, the total number of minority persons served by all of the public agencies is less than those served by private agencies. The public schools are one of the most important types of public agencies

serving the younger disabled, and some studies detail the services they offer, particularly for the mentally retarded.[1]

Participants at the meetings suggested that outreach activities may help increase the level of minority participation. This was supported by our study and has been documented by many other studies.[2] As our survey showed, agencies using an outreach program to reach minorities have more minority clients than agencies which do not use this method. However, our data does not allow us to infer why this association exists.

On the other hand, the results of our study were somewhat inconsistent with the strong perception of meeting participants that minority persons do not have full knowledge and do not fully utilize the services and programs of nearby agencies. Most of the agencies sampled reported that they have outreach programs and that minority persons in their areas know about and use their services to the fullest. Agencies with no outreach program frequently reported that they did not have one because the community was already aware of their services, and did not need an outreach effort. Since we did not systematically sample the minority disabled population in these areas, we do not have the information to resolve this issue.

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[1] See California Department of Health, Office of Planning and Program Analysis, 1973; Cohen, 1968; Ford, 1975; Lei, 1974; McGrath, 1960; and Williams, 1968.

[2] See Justice, et al. In "Problems Reported by Parents of Mentally Retarded Children; Who Helps," 1971; Western Interstate Commission for Higher Education, "Four Corners Mental Retardation Project: Training and the Use of Indigenous Aides in a Sparsely Populated, Economically Different Region," 1969; Long, "Annual Report on Project Impact and Project Star," 1978; and Cawley, "Learning Aptitudes Among Preschool Children of Different Intellectual Levels," 1968.

Another finding was that more agencies, and particularly state agencies, were located in rural areas than urban areas. Participants at the meetings preferred urban locations because they felt these would be more accessible to minority persons. They felt this was because urban areas tended to have more minority persons than rural areas, and presented fewer transportation problems -- often a hurdle to minority participation. However, in considering how well an agency serves minority needs, location must be considered along with other factors, such as budget, agency size, etc. as pointed out by two studies by Reschly et al. (1976)[3] and Sontag (1972).[4] For example, even though there may be more agencies in rural areas, agencies in urban locations tend to have larger budgets, and so can serve more clients. This may explain why state agencies (who have larger budgets) tend to be located in rural areas, tend to serve more minority clientele (who tend to be urban based) than other agencies.

It must be noted, however, that the factor complicating designating agencies by urban or rural location is that the sampled agencies and the Census Bureau may use different definitions for urban and rural. For example, when we examined some of the state agencies located in a rural area, we found that many were district or county units of state agencies, and many of these were residential institutions operated by state departments, such as state hospitals and special institutions designed to be located in areas remote from heavily populated regions.[5]

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[3]Reschly et al. (1976), "Ethnicity, Geographic Locale, Age, Sex, and Urban/Rural Residence as Variables in the Prevalence of Mild Mental Retardation."

[4]Sontag (1972), "Programs for American Indians and Alaskan Natives."

[5]See Thurlow, et al. in "Deinstitutional and Residential Services: A Literature Review," (1978).

There was also some discrepancy in the views of agencies and meeting participants on the needs of minority disabled persons. Although those at the meetings generally agreed that minority needs are different, the sampled agencies who made open-ended comments on the questionnaire about the unmet service needs of the minority population, challenged this view. Generally, they remarked that the developmental needs of individual clients are more important than race, or they pointed out that the needs of minority and non-minority clients are the same in various ways. For example, they felt that all share the need to be accepted, to be reasonably accomodated, to be given opportunity, and to be gainful, productive citizens.

Nevertheless, a number of agencies did list some unmet minority needs, based on open-ended comments as part of the survey questionnaire (Section V). Specifically, some pointed to the failure of the service delivery system to bring the minority client and the professional into the mainstream of the DD movement. As one participant pointed out, certain factors contribute to the minority disabled being organizationally and historically isolated from the movement, such as a lack of national, state, and local efforts to relate specifically to minority problems, and a failure to identify minority problems with national causes, such as United Cerebral Palsy and the National Association for Retarded Citizens. Such factors prevent minorities from seeking services.

In response to these deficiencies, some agencies suggested they should do more outreach and develop ethnically oriented materials. Other suggested that agencies develop ways to make minority group members less defensive and apprehensive about seeking services. For example, one agency commented

that "families need to be helped to acknowledge the existence of the disability and the need for remediation." Also, some agencies felt the educational system should change some of its policies, such as placing minority children in EMR classes, when they had other needs.

However, while some blame was attributed to the service system, some agencies tended to place some blame for the low levels of minority participation on the minority community itself. For instance, one respondent felt that the minority community could increase its use of certain resources, which were not being effectively utilized. As an example, families often tend to delay seeking treatment for a disability, and thus they do not effectively utilize available physicians.

In other cases, the family's limited resources may serve as a block itself. For instance, due to low incomes, some families may lack transportation, and thus find getting to some service locations difficult or impossible.

In sum, the survey data and open ended agency comments are generally consistent with the views about minority participation held by participants at the nationwide meetings, though there were a few surprises. Nevertheless, there is still a need for more detailed and systematic assessments of participation and the services offered. This assessment must involve both consumers, as well as providers, and importantly, should address the difficult problem of measuring the needs of developmentally disabled persons not registered with agencies and therefore not readily accessible.

The present study to quantify existing minority participation and related areas will provide the necessary data base by which to compare future improvements in minority recruitment and participation from the

agency point of view.[6] It is becoming increasingly necessary to receive local input on the best alternative services for each community. Minority participation in strategies and implementation are, in turn, essential to proper understanding, development, location and utilization of services in minority communities. And among minority populations where a sense of neighborhood, ethnic origins and languages remain strong, use of neighborhood workers and bilingual materials will facilitate entry, understanding, and participation.

Minority involvement in decision-making is particularly crucial for eventual satisfaction of unmet needs. The Supplement to the 1976-77 Developmental Disabilities Plan for Alameda County, California, lists, in addition to the need to intensify work with minority populations, such other areas as:

- Accessibility, including elimination of architectural barriers.
- Activity and training programs.
- Counseling for developmentally disabled and parents/care home administrators.
- Day care for the developmentally disabled.
- Definition (clarification) of autism and neurologically handicapped.
- Early intervention and prevention programs.
- Education.
- Health and mental health.
- Manpower training and development.
- Outreach to minority and low-income groups; develop bilingual materials.
- Public education.
- Residential care.

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[6] Two related reports which address this problem are Ruth Murphy, Why Minority Individuals With Developmental Disabilities Drop Out of the Service System, A Report to the Wisconsin Council on Developmental Disabilities, November 1978; and Developmental Disabilities Task Force, Participation of Minorities in the Developmental Disabilities Movement in The Twin Cities Metropolitan Area, An Assessment, Metropolitan Council Health Board, February 1979. Both reports suggest the quantity and quality of minority participation may be increasing since the inception of the present study.

- Social and leisure time activities.
- Transportation.
- Vocational services.

And these are the unmet needs of a primarily White population.

Minority populations face additional difficulties that relate directly to the success of prevention and treatment programs.

For instance, the Minority Affairs Coalition noted in its October, 1975 Bulletin, that 75 percent of mild retardation occurs in poverty areas where significant cause and effect role is played by such preventable environmental factors as:

1. Malnutrition - Increasing evidence indicates that malnutrition of a pregnant woman can cause brain damage in her child. Malnutrition can make children susceptible to disease.

2. Poor Medical Care - High population density, chronic poverty, chronic illness, untreated physical and mental disorders, unattended pregnancies, unsanitary environment conditions, malnutrition, poor health and lack of protection from pollution are all common in poverty areas and are the basic factors which cause mental retardation.

3. Cultural Deprivation - Poor environment, poor nursery and day care programs, reinforcement of a sense of failure and minimal living quarters all add to the lack of stimulation available for a child growing up in poverty.

4. Health Hazards - Besides a poor diet, lead-based paint, inadequate washing and toilet facilities and crowded living conditions can cause disease. The incidence of infectious and non-infectious illness in poverty areas are notoriously higher than the average.

5. Other Related Factors include inadequate welfare training programs, family planning, child abuse, identification systems and procedures, and social attitudes.

- National Minority Affairs Coalition Beacon, Volume I, No. 2: October, 1975

Without equitable representation in service decisions, special needs like those above may continue to go unaddressed, and case-finding and provision of regular services may continue to be lower among non-white populations.

VIII. RECOMMENDATIONS AND SUGGESTED ACTION PLANS

One of the objectives listed in our proposal to HEW was to compile a list of recommendations and plans of action designed to increase the level of minority participation in the DD movement. The recommendations are based on the entire project and are organized into four categories; recommendations by agencies, by parents and consumers, by project staff, and unanswered research questions uncovered in the course of the study, especially those dealing with unmet minority needs. They are as follows:

1) Recommendations based on comments by agencies to Section V of the survey question (Appendix F). These recommendations are responsive to the comments made by service providers on the questionnaire about unmet service needs. Some of these needs characterize the DD population as a whole, since many providers felt it was not possible to distinguish minority and non-minority needs. To fill these needs, as recommended by the service providers, it is recommended that certain changes be made in the service system itself to make providers better able to meet both minority and non-minority clients' needs. These include the following:

In Housing:

- the provision or improvement of housing of various types, including community living facilities, independent living programs, group homes, residential facilities, foster and adoptive homes, and specialized homes providing special services, such as intensive training, behavior management, and care for non-ambulatory clients

In Transportation:

- the provision or improvement of transportation to services and recreation activities
- the provision of barrier free transportation

In Education and Information:

- the addition or expansion of outreach programs to inform developmentally disabled families about services
- the provision of education for the community at large, and particularly for community groups, medical personnel, and law enforcement persons, about the developmentally disabled
- the development of key education and training programs for the developmentally disabled, including training on developing skills to live independently; family life; and sex education
- the provision of developmental services for children and for the severely handicapped
- the development of ethnically oriented materials for use with minority DD persons
- the development of materials and procedures for making minority DD persons less defensive and less apprehensive about seeking services

In Recreation:

- the provision or improvement of recreational services, including therapeutic recreational services

In Employment and Income:

- the provision of employment, particularly competitive employment
- the provision of supplemental income to low-income disabled families

In Medical:

- the provision of medical screening for medically indigent and low-income families
- the provision of early screening, diagnosis, and intervention for developmentally delayed disabled children
- the provision of certified quality nursing home care for the disabled needing on-going constant medical care
- the provision of full-time and emergency respite care facilities for those needing such care

In Legal and Criminal:

- the provision of advocacy services

- the provision of alternatives to incarceration for emotionally inflicted youth

- the provision of training for board members and staff on their roles and responsibilities, and on ways of developing an increased sensitivity to the disabled

- the provision of in-service training programs on specific techniques and issues of concern

- the provision of additional staff to provide minimal supervision for the mentally retarded in community living arrangements

- more funds to expand and/or improve services

- more funding for rural programs

- a more adequate counseling staff

- more bilingual/bicultural staff members

In Research:

- Further research is needed involving minority consumers to further identify unmet needs. This is recommended, since the needs for services and system improvements identified by providers tend to be stated in only a general way, so accurate assessment is not possible. Also, providers do not generally have specific information on the minority population, or do not feel it realistic to separate the minority and non-minority needs, since they consider family income level and disability severity more important in determining needs than race or ethnicity.

2) Recommendations and Plan of Action for State Developmental Disabilities Councils, Planning Councils and other policy and planning bodies. These recommendations are based on project staff's perception of unmet needs resulting from field experiences direcly related to study activities and suggest strategies for increasing effective participation of minorities of all levels in the DD movement.

- It is recommended that service agencies take steps to inform minority consumers of board and advisory committee meetings and provide support services (such as assistance with transportation and babysitting), so that minority consumers are better able to attend.

- It is recommended that DD Councils in cooperation with minority groups develop lists of names of minority persons interested in serving on the boards of agencies and organizations which fund, monitor, plan for, regulate, and/or evaluate the delivery of services. Further, it is recommended that these names be circulated to local DD service providers, and that these lists be used in making recommendations for membership.

- It is recommended that the DD Council conduct periodic training workshops for DD agencies on how to expand minority participation in DD services.

- It is recommended that agencies serving minority clients and those in areas with a large number of minority clients compile information on the unmet needs of these populations.

- It is recommended that any information compiled by an agency on the unmet needs of minority clients be submitted to the state DD Council for inclusion in the State Plans, so that funding priorities can be established in serving the minority developmentally disabled.

- It is recommended that state DD Councils prepare a statewide list of organizations serving the developmentally disabled, and include in this list both public and private agencies, and any programs receiving public or other funds. The Councils should periodically update these lists and circulate them widely. This is recommended, since there is a lack of organized information on the availability and nature of DD services.

- It is recommended that state DD Councils establish a toll-free information number, and that a national clearinghouse on minority DD information be established. This is recommended, since there is a need for an easily accessible source of information on the minority developmentally disabled.

- It is recommended that the Federal Government coordinate its various data gathering activities and require that all organizations serving the disabled include information on the race/ethnicity of clients and projections on the race/ethnicity of the unserved population in their area. This is recommended, since Federal departments and agencies have conflicting, confusing, or non-existent requirements for the collection of data on clients and unserved persons.

- It is recommended that the Bureau of Developmental Disabilities fund studies to establish the incidence and prevalence of developmental disabilities among minority and low income persons, and to provide information on the service needs of minority disabled not receiving any services. This is recommended, since figures on DD prevalence are not categorized by race/ethnicity, nor for low income status. It is important to have such data, since research

suggests that low-income status may create conditions leading to higher prevalence rates among low-income and minority persons.

- It is recommended that the Bureau of Developmental Disabilities require that the membership of a state DD Council reflect the racial and ethnic composition of that state's population. This is recommended, since minorities are currently poorly represented on these Councils, and because Federal agencies, and in particular, the Bureau of Developmental Disabilities, currently provide little direction on how to expand and/or improve minority participation on state DD Councils.

- It is recommended that the DD Council in preparing the State Plan each year, select a sample of representative agencies to collect data on the numbers of minority persons served and those needing services. Such data should be included in the State Plan. This is recommended, since regulatory and funding agencies lack documentation on the numbers of minorities served and those needing services.

3) Recommendations from Parents and Consumers Attending the Nation-wide meetings. These recommendations are responsive to the needs of minorities as perceived by parents and consumers. They also reflect the views of parents and consumers on how minorities should participate in service delivery, planning, policy formation, and decision-making in DD programs. Although only about 500 participated in these national meetings, the participants were representative of those in the DD movement, and their recommendations supplement and complement those developed from the quantitative survey and provide the only input to study from minority parents and consumers.

At the national meetings, parents and consumers made three types of specific recommendations -- to service providers, to parents of the developmentally disabled, to DHEW. In addition some general recommendations were made. The following recommendations reflect their views on how minorities should participate in service delivery, planning, policy formation, and decision-making in DD programs:

The meetings provided participants an opportunity to interact and discuss their concerns with each other, which contributed valuable insights not obtainable through a mail survey. However, one limitation is that, while every major ethnic group was represented at the meetings, only a limited amount of time could be spent discussing issues of concern to a given ethnic group. As a result, while common concerns for each population group were identified, specific concerns could not be explored in any depth.

A second limitation is that the information obtained at the meetings relied solely on the perceptions of the participants, which may sometimes be inaccurate. For example, attitudes affect and may distort the way an individual recalls a service he has received. While some people are thankful for whatever help they receive, others are instinctively mistrustful. Some may even forget receiving or having a service offered if they were not interested in it or did not like it. Similarly, the perception of agency representatives can be subject to distortion.

But in spite of these limitations, the views of participants are necessary for a complete examination of participation in the DD movement.

Note: Several references provided us direction in the sampling and follow-up. The major ones were Leslie Kish, Survey Sampling, New York, J. Wiley, 1965; J.R. Hinrichs, "Factors Related to Survey Response Rates," Journal of Applied Psychology, 60 (November 2, 1975) pp. 249-251; Stanley S. Robin, "A Procedure for Securing Returns to Mail Questionnaires," Sociology and Social Research 50 (October, 1965) pp. 24-35; and Lee Robins, "The Reluctant Respondent" Public Opinion Quarterly 27 (Summer 1963) pp. 276-86.

APPENDIX E

SAMPLING DESIGN AND CALCULATION OF STANDARD ERROR

From the total universe of 23,817 agencies, we decided to aim for a sample size of 1200. This was decided based on two main considerations -- the unit cost of sampling (relative to the available budget) and the desired level of precision in estimating parameters, which are the factors usually taken into account in studies of this kind.

The level of precision is obtained from the formula for the binomial standard error $S = \sqrt{(pq)/n}$, where p is the proportion of the population having a certain attribute, $q = 1 - p$, and n is the sample size. It is usual to replace p by .5. Given cost limitations, we adopted a sample size of 1200 because the resulting standard error of estimating parameters, such as the proportion of agencies possessing a certain attribute, would be no more than .014 (or 1.4%). This would give us a 95% confidence interval of about $\pm$ 2.8%.

Another advantage of this sample size was that if we were interested in looking at the parameters of subsets of agencies (such as the proportion of rural agencies possessing an attribute), we could maintain a 95% confidence interval narrower than $\pm$ 6%, as long as more than 25% of our sample was in the subset. Since we considered a 95% confidence interval narrower than $\pm$ 6% acceptable, we felt our choice of 1200 justifiable.*

Once the sample size was selected, the next step was to decide how to select the 1200 agencies. This decision was influenced by two considerations. First, since we recognized that the universe of agencies is probably very heterogeneous (e.g., composed of public and private, rural and urban agencies), we felt that stratified sampling would lead to more

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*These estimates of precision suggested that a sample size of 1200 would be desirable. However, the actual sample size on which our analyses are based is 732. This means that the actual levels of precision in the present study are about 30% greater than would have been the case with a sample size of 1,200.

precise estimates than would random sampling from our complete national list. Secondly, since we had as our primary interest the participation of minority persons, we felt it desirable to focus on those agencies with a moderately large percentage of minority clients, more so than those with a small percentage of such clients. However, since the percentages for the agencies were unknown, we decided to use as a proxy, the percentage of minority persons.

To define our "region" or stratum, we used a unit for which the population distribution by ethnic group was available. Although these distributions are available from regions as small as the Standard Metropolitan Statistical Areas used in Census reports, it is more usual and simpler to use a small number of strata in stratified sampling. Thus, we chose as our "regions" the 10 regions defined by the Department of Health, Education, and Welfare.

To stratify our sample, we followed this procedure. Using the agency parameter of 23,817, we calculated the proportion (a_i) of minority persons per region, as indicated in the 1970 Census data by dividing the total number of minorities in each of the 10 regions by the total population of each region. The results were:

Region	Percent
I	.05
II	.19
III	.15
IV	.24
V	.11
VI	.31

[1] Although it would seem more logical to use the percentage of minority DD persons in the region, these percentages are based on estimates of prevalence rates that are not very reliable, whereas the percentages of minority persons are available in the Census data. To the extent that the true prevalence rates are uniform across regions, there would be little difference in using one set of percentages rather than the other.

Region	Percent
VII	.07
VIII	.10
IX	.28
X	.06

With this information, we were then ready to proceed with our disproportional sampling plan. This plan selects agencies, n_i, based upon both proportion of agencies in region and proportion of minorities. The formula is $n_i = c\sqrt{a_i N_i}$: where c is a constant adjusted so that the n_i's add up to 1200, and a_i is the proportion of minorities/region in the nation. The calculation involves five steps, they are:

Step 1 $\sqrt{a_i}$ for each region

Step 2 $\sqrt{a_i} \times N_i$ for each region

Step 3 sum of Step 2

Step 4 divide results of Step 2 for each region by the sum in Step 3

Step 5 multiplying results of Step 4 for each region by 1200, the sample size

As a result of the computations, we selected the following number of agencies to be sampled for each region:

Region	n_i
I	50
II	50
III	170
IV	310
V	190
VI	70
VII	80
VIII	70
IX	180
X	30

Please Note: In this plan, the standard error measurement for each region is less than 10% (it reaches this level only for Region X), and we found this very acceptable.

Then, to select the requisite number of agencies from the total agency universe for each region, we obtained a skip factor, k, by dividing the number to be sampled by the total number of agencies in that region. Using this factor, we selected every k'th agency up to the desired sample size. Since we expected a non-response of about 25%, we increased the sample size by 25%, and then mailed the questionnaire to the selected sample.

Responses were received from 844 of the 1,500 agencies that received the questionnaire. Of the 844 respondents, 732 included sufficient information for their questionnaire to be included in the data analysis. Every effort was made to obtain a high response rate. Prior to mailing the questionnaire, we sent an introductory letter in February 1979 to all agencies in the sample advising them of the survey and its purpose. In about 100 cases, we discovered incorrect addresses and names of contact persons, or found agencies no longer in operation. We then made the appropriate corrections and replacements.

In March, we mailed the questionnaires. After approximately 260 responses were received by late April, we contacted non-respondents by phone and by mailgram. In mid-June we mailed a second copy of the questionnaire to non-respondents along with a letter from the Director of the Bureau of Developmental Disabilities, emphasizing the importance of the study. We mailed a third questionnaire in late July.

Detailed Rationale for Sampling Plan

Our rationale for adopting a disproportional sampling plan was based on two models for obtaining approximate estimates of the precision estimated population parameters.

The first model enabled us to get the approximate precision of

estimates of the proportion of agencies in the nation that have a specified characteristic. Mathematically, this model can be stated as follows: let p be this proportion and let p_i be the proportion of agencies in the i'th Region that have the characteristic. Let $\hat{p}$ denote our estimate of p, and $\hat{p}_i$ our estimate of p_i. N_i and n_i are the numbers of agencies in the universe and sample, respectively, from the i'th Region.

Then $\hat{p}$ is the following weighted average:

$$\hat{p} = \sum_{i=1}^{10} \frac{N_i}{N} \hat{p}_i ,$$

where $N = \sum_{i=1}^{10} N_i$. Since the estimate $\hat{p}_i$ is based on a sample size of n_i,

$$\text{var } (\hat{p}_i) = \frac{p_i (1 - p_i)}{n_i} .$$

Therefore,

$$\text{var } (\hat{p}) = \sum_{i=1}^{10} \frac{N_i^2 p_i (1 - p_i)}{N^2 n_i} .$$

To approximate this expression, we assume that

$p_i = p$, $i = 1, ---, 10$, so that

$$\text{var } (\hat{p}) = \frac{p(1 - p)}{N^2} \sum_{i=1}^{10} \frac{N_i^2}{n_i} . \qquad (1)$$

This expression is minimized, subject to

$$\sum_{i=1}^{10} n_i = 1200,$$

by putting n_i proportional to N_i. Therefore, to obtain the agencies in region i, we would sample from our list of agencies with a skip interval of N_i/n_i (e.g., in region I, N_i = 1663 and n_i = 80, giving a skip interval of 1663/80 = 21).

The second model enabled us to get the approximate precision of estimates of the proportion of minority DD clients that have a certain characteristic. Mathematically, this model can be stated as follows: let M_i be the DD population in the i'th region; and let a_i be the proportion of minority <u>persons</u> in the region, and a be the proportion for the nation. Let m_i be the number of DD persons associated with the agencies in our sample from the i'th Region. Let q denote the proportion of minority DD persons in the nation that have the characteristic, and let q_i be the proportion for the i'th Region. Since there are $a_i M_i$ minority DD persons in Region i, the weighted average for $\hat{q}$ is:

$$\hat{q} = \sum_{i=1}^{10} \frac{a_i M_i}{aM} \hat{q}_i ,$$

where $M = \sum_{i=1}^{10} M_i$.

The estimate $\hat{q}_i$ is based on a sample size of approximately $a_i m_i$, so that

$$\text{var}(\hat{q}) = \sum_{i=1}^{10} \left(\frac{a_i M_i}{aM} \right)^2 \frac{q_i(1 - q_i)}{a_i m_i} .$$

If, as before, we assume $q_i = q$,

$$\text{var}(\hat{q}) = \frac{q(1 - q)}{a^2 M^2} \sum_{i=1}^{10} \frac{(M_i \sqrt{a_i})^2}{m_i} . \qquad (2)$$

By analogy with Eq. (1), we see that the expression in Eq. (2) is minimized when m_i is proportional to $M_i \sqrt{a_i}$.

To make this analysis relevant to our purposes, we assumed (a) that M_i is proportional to N_i, and (b) that m_i is proportional to n_i. It would then follow that n_i should be chosen so as to be proportional to $N_i \sqrt{a_i}$.

Significantly, in this disproportionate sampling plan the sampling fraction n_i/N_i varies from region to region with the proportion of minorities in the region. Because of this variation, there is a lower likelihood than under proportional sampling that agencies catering to the less numerous ethnic groups, such as Native Americans, will be omitted. When we designed the study, this consideration was important to us, because we had planned to interview clients of agenices, and we felt this disproportional sampling would improve our chances of reaching a large number of minority clients.

The data presented earlier in this report consisted of percentages of <u>agencies</u> in various categories. As before, let $\hat{p}_i$ be the proportion for the i'th Region. Then the national estimate $\hat{p}$, is the weighted average

$$\hat{p} = \sum_{i=1}^{10} \frac{N_i}{N} \hat{p}_i ,$$

where the values of N_i/N are given in Table H1 in Appendix H. The standard error of $\hat{p}$ is

$$S = \left[\sum_{i=1}^{10} \frac{N_i^2 p_i (1 - p_i)}{N^2 n_i'} \right]^{1/2} ,$$

when n_i' is the number of agencies in Region i that provide data for the computation of $\hat{p}_i$. Almost always n_i' is less than n_i, the number of usable

questionnaires from Region i. (To get the estimated percentage and its standard error, we multiply $\hat{p}$ and S by 100.) A simplification that yields a very good approximation for S is obtained by replacing n_i' by $R_j n_i$, where R_j is the response rate (proportion) for the whole sample, for the relevant questionnaire item (j). Thus, the standard error of $\hat{p}$ (based on the responses to questionnaire item j) is

$$S \simeq \frac{1}{\sqrt{R_j}} \left[\sum_{i=1}^{10} \frac{N_i^2 p_i (1 - p_i)}{N^2 n_i} \right]^{1/2} .$$

To calculate the standard error of the national estimate of the median of a distribution, we proceed as follows. Suppose that the variable in question is, e.g., size of total staff. Let us define f(x) to be the proportion of agencies that have a total staff size of exactly x. Let x_m be the true median of the distribution, and let $\hat{x}_m$ be the estimate of x_m based on a homogeneous sample of size n. Then, it is known that the standard error of x_m is given approximately by

$$S.E.(\hat{x}_m) = \frac{1}{2f(\hat{x}_m)\sqrt{n}} .$$

(See, e.g., S.S. Wilks, Mathematical Statistics, 1962 (Wiley), p. 273.) The term $1/2\sqrt{n}$ in the above expression is the standard error of our estimate of the proportion of agencies with a total staff size of x_m or more. Thus, the analog of this term for our case of a stratified sample is the standard error given for the appropriate category in the Table 1 in Section VI. The standard error would then be

$$S.E.(\hat{x}_m) \simeq \frac{S}{f(\hat{x}_m)} ,$$

where $f(\hat{x}_m)$ is obtained from the relevant Table in Section VI.

An example would illustrate this method for the estimated size of total staff. The unknown median of the distribution of staff size is x_m. We assume that the standard error of the estimated proportion of agencies with staff size of over x_m is about the same as that of the estimated proportion when x_m is replaced by 20. This latter standard error is given in line 8 of Table 1 as 0.019. Next, we have to estimate $f(\hat{x}_m)$. From Table 3, x_m lies in the range 11 to 20. Also, the proportion of agencies with staff sizes equal to one of these ten values is 0.41. Assuming that this proportion is evenly divided among the ten values, we get that $f(\hat{x}_m) \simeq 0.41/10 = 0.041$. Therefore,

$$S.E.(\hat{x}_m) \simeq \frac{S}{f(\hat{x}_m)} = \frac{0.019}{0.041} = 0.46 \quad .$$

However, as noted in the general discussion of methodology, these estimates of standard error are only rough indices of the precision of our estimates. Nevertheless, our estimates based on medians are probably more reliable than if we had used averages, because our sample is very heterogeneous, in that it ranges from private agencies with less than 10 clients to state hospitals with over 2000 clients. Given this much variability, the median is generally closer than the average to what is typical, since the average or mean is extremely sensitive to extreme values.

APPENDIX F

QUESTIONNAIRE FOR PROVIDERS OF
DEVELOPMENTAL DISABILITY SERVICES

NEW
DIMENSIONS IN COMMUNITY SERVICE, INC.
NATIONWIDE STUDY ON MINORITY PARTICIPATION IN DEVELOPMENTAL DISABILITY PROGRAMS

4444 Geary Boulevard • Suite 210 • San Francisco, California 94118 • (415) 387-4114

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ROBERT E. STAPLES, Ph.D.
KATHRYN WITCHER, M.S.W.

March, 1979

Dear Colleague:

The Office of Human Development Services, Bureau of Developmental Disabilities, Department of Health, Education, and Welfare has funded New Dimensions in Community Service, Inc., a non-profit human services organization, to design and undertake a nationwide evaluative and fact-finding survey of minority participation in the developmental disabilities movement. Your agency was one of those randomly selected to participate in the study.

This survey is being conducted under the authority of P.L. 94-103, the Developmentally Disabled Assistance and Bill or Rights Act of 1975. This act has now been amended by P.L. 95-602, Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978. Your cooperation, by responding, is very necessary to make the results comprehensive, accurate, and timely. The information from this survey will be made available through reports in aggregate form without identifying individuals, which fulfills the Government's obligations under the Freedom of Information Act of 1975 (5 U.S.C. 552). The lists linking names and code numbers will be kept with the grantee. At no time during this survey is a "system of records" created as that term is defined in the Privacy Act Statement (5 U.S.C. 552 A (a) (5)). Therefore, the Privacy Act Statement has no effect on this survey.

At the end of the study you will receive a report which summarizes agency responses to the questionnaires, and makes recommendations on how agencies might improve or expand minority participation. Concerns and comments of developmentally disabled persons and parents will be included. Please note: Your agency's completed questionnaire should be returned in the enclosed self-addressed envelope by April 9, 1979.

Thank you for your cooperation.

Sincerely,

Beverley J. Morgan

Beverley J. Morgan,
Project Director

BJM:et

A private non-profit, tax exempt organization

Fosters participation in solutions to problems affecting health, education, economic and social well-being of the individual and family through self-help, self-determination and community awareness

O.M.B. #85 S78005
September, 1979

QUESTIONNAIRE FOR PROVIDERS OF DEVELOPMENTAL DISABILITY SERVICES

This study and subsequent report are authorized under P.L. 94-103,* the Developmentally Disabled Assistance & Bill of Rights Act of 1975, as implemented under the auspices of the Department of Health, Education, and Welfare, Washington, DC, Office of Human Development Services, Bureau of Developmental Disabilities.

The information from this survey will be made available in aggregate form without identifying individual groups, organizations or agencies; which fulfills the Governments obligations under the Freedom of Information Act of 1975 (5 USC 552). Any list linking names and code numbers is confidential and is kept with New Dimensions in Community Service, Inc.(the grantee). At no time during this survey is a "system of records" created. Therefore, the Privacy Act has no effect on this survey.

To assist in your responses to questionnaire items, the following definitions are given:

MINORITY:

American Indian or Alaskan Native: A person having origins in any of the original peoples of North America, and who maintains cultural identification through tribal affiliation or community recognition.

Asian or Pacific Islander: A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, Japan, Korea, Philippine Islands, and Samoa.

Black (not of Hispanic Origin): A person having origins in any of the Black racial groups of Africa.

Hispanic: A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.

WHITE:

White (not of Hispanic origin): A person having origins in any of the original peoples of Europe, North Africa or the Middle East.

DEVELOPMENTAL DISABILITIES:

A disability of a person which is attributable to such conditions as mental retardation, cerebral palsy, epilepsy, autism, and dyslexia and those defined in P.L. 94-103.

PLEASE NOTE: DATA SHOULD BE REPORTED AS OF SEPTEMBER 30, 1978, OR THE NEAREST CONVENIENT DATE PRIOR TO. IF OTHER THAN SEPTEMBER 30, 1978, PLEASE GIVE MONTH _____ AND YEAR _____ FOR WHICH YOU ARE REPORTING.

Questionnaires should be returned by April 9, 1979, in the enclosed self-addressed envelope.

Questionnaire completed by: _____
(Name) (Title)

_____
(Agency Name)

_____
Address (Number & Street) City State

_____
(Zip Code) (Area Code) (Telephone Number)

*This act is now amended by P.L. 95-602, Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978.

SECTION I: AGENCY INFORMATION

1. What kind of agency is your organization? (Place a check (✓) mark in the box next to the classification that most nearly describes your agency.)

- [ ] 1. State Government Agency
- [ ] 2. Local Government Agency
- [ ] 3. Private, non-profit
- [ ] 4. Private, profit
- [ ] 5. Other (describe) _____

2. For how many years has the agency served the developmentally disabled? (Check only one.)

- [ ] 1. Less than 1 year
- [ ] 2. 1 - 2 years
- [ ] 3. 3 - 5 years
- [ ] 4. 6 - 10 years
- [ ] 5. More than 10 years

3. What is the agency's largest source of funding for services to your clients who are developmentally disabled? (Check only one.)

- [ ] 1. Federal Government
- [ ] 2. State Government
- [ ] 3. Local Governments (City and County)
- [ ] 4. Foundations and other private groups
- [ ] 5. United Way, Community Chest, or other voluntary fund-raising source
- [ ] 6. Membership fees
- [ ] 7. Client fees
- [ ] 8. Other (specify) _____

4. What is the dollar amount of the agency's annual budget for services to clients who are developmentally disabled? (Check only one.)

- [ ] 1. $100,000 or less
- [ ] 2. $100,001 to 500,000
- [ ] 3. $500,001 to 900,000
- [ ] 4. $900,001 to 2,000,000
- [ ] 5. $2,000,001 or more

5. What is the total population of your catchment (service) area? (Check only one.)

- [ ] 1. 49,000 or less
- [ ] 2. 49,001 to 100,000
- [ ] 3. 100,001 to 500,000
- [ ] 4. 500,001 to 900,000
- [ ] 5. 900,001 to 2,000,000
- [ ] 6. Over 2,000,000

6. What proportion of the population of the catchment area are minority? (Please estimate if unknown.)

- [ ] 1. 5% or less
- [ ] 2. 6 - 10 %
- [ ] 3. 11 to 20%
- [ ] 4. 21 - 30%
- [ ] 5. Over 31%

7. How would you describe the area in which your agency is located? (Check only one.)

- [ ] 1. Rural
- [ ] 2. Urban
- [ ] 3. Suburban
- [ ] 4. Reservation
- [ ] 5. Other (describe) _____

SECTION II: STAFFING

PLEASE NOTE: You will need to have information available on paid and volunteer staff, and minority and non-minority staff. Definitions of staff categories are as follows:

ADMINISTRATIVE STAFF: Persons who set broad policies, exercise overall responsibility for execution of these policies, or direct individual departments or special phases of the agency/organization's operation; including, but not limited to, executive directors, program and fiscal managers, planners, supervisors, etc. Also, persons responsible for staff development or in-service training programs are included under this category.

DIRECT SERVICE STAFF: Persons (professional/para-professional) who work directly (or in support capacity) with developmentally disabled persons and their families; including, but not limited to, social workers, counselors, house parents, medical or para-medical, etc.

CLERICAL STAFF: Persons who are responsible for internal and external communications, recording, and other paper-work, required in an office; including, but not limited to, clerks, receptionists, secretaries, and so on.

OUTREACH STAFF: Persons responsible for community organization and education, (i.e., interpreting agency programs and services), and for identifying potential clients and community resources.

VOLUNTEER STAFF: Persons who provide a service on a non-paid basis, and who work in concert with paid staff towards shared agency/organization objectives.

8. How many persons are employed by the agency/organization in the categories listed?

INSTRUCTIONS:

Please read definitions of racial/ethnic categories (see front page), and of staff categories (see chart below) before you begin.

On the chart below, indicate the number of paid staff members who are developmentally disabled (DD), or not developmentally disabled (NON-DD), by race/ethnicity.

The sum of Rows 2 and 3 should equal to Row 1, and the sum of Rows 4 through 7 should equal to Row 3.

	Administrative		Direct Service		Clerical		Outreach	
	DD	NON DD	DD	NON DD	DD	NON DD	DD	NON DD
Row 1 [ ] TOTAL PAID STAFF								
Row 2 [ ] TOTAL WHITE (not of Hispanic Origin)								
Row 3 [ ] TOTAL MINORITY								
Row 4 [ ] American Indian or Alaskan Native								
Row 5 [ ] Asian or Pacific Islander								
Row 6 [ ] Black (not of Hispanic Origin)								
Row 7 [ ] Hispanic								

9. How many persons volunteer with the agency/organization in the categories listed?

INSTRUCTIONS:

Please read definitions of racial/ethnic categories (see front page), and staff categories (see page two).

On the chart below, indicate the number of volunteer staff who are developmentally disabled (DD), or not developmentally disabled (NON-DD), by race/ethnicity.

The sum of Rows 2 and 3 should equal to Row 1, and the sum of Rows 4 through 7 should equal to Row 3.

	Administrative		Direct Service		Clerical		Outreach	
	DD	NON DD	DD	NON DD	DD	NON DD	DD	NON DD
Row 1 [ ] TOTAL VOLUNTEER STAFF								
Row 2 [ ] TOTAL WHITE (not of Hispanic Origin)								
Row 3 [ ] TOTAL MINORITY								
Row 4 [ ] American Indian or Alaskan Native								
Row 5 [ ] Asian or Pacific Islander								
Row 6 [ ] Black (not of Hispanic Origin)								
Row 7 [ ] Hispanic								

10. Does your agency/organization sponsor in-service training programs for staff and volunteer personnel on the culture, attitudes, and expectations of minority groups?

[ ] 1. Yes
[ ] 2. No

11. If not, what are the reasons?

[ ] 1. No minorities in service area
[ ] 2. Not necessary -- we are a minority agency with all minority staff
[ ] 3. Cost of in-service training programs not in budget
[ ] 4. Other (specify) _____

12. What is the method most often used by the agency to recruit staff (paid and volunteer)?

INSTRUCTIONS:

Please read the definition of racial/ethnic categories (see front page), before beginning.

Complete the chart below for paid and volunteer staff by indicating a check (✓) mark for the method most often used to recruit each racial/ethnic category.

	Word of Mouth	Other Agencies	Professional Journals	Civil Service	Newspaper, Radio /TV	Employment Agency	Agency Staff Recommendations	Community Organizations, Persons or Groups
PAID STAFF								
WHITE (not of Hispanic Origin)								
MINORITY								
American Indian or Alaskan Native								
Asian or Pacific Islander								
Black (not of Hispanic Origin)								
Hispanic								

VOLUNTEER STAFF*								
WHITE (not of Hispanic Origin)								
MINORITY								
American Indian or Alaskan Native								
Asian or Pacific Islander								
Black (not of Hispanic Origin)								
Hispanic								

*Persons who are volunteers and who function in administrative, direct service, clerical or outreach staff positions.

SECTION III: SERVICES

This section requests information on the agency/organization's programs, services and clientele. Please read the instructions carefully before responding.

13. What proportion of clients served by your agency have a developmental disability? (Check only one.)

- [ ] 1. 90 to 100%
- [ ] 2. 50 to 89%
- [ ] 3. 11 to 49%
- [ ] 4. Less than 10%

14. What is the age group of the developmentally disabled clients served by your agency? (Place a '1' in the box indicating the age group where you have the largest number of developmentally disabled clientele, a '2' in the box of the age group where you have the second largest number, and a '3' in the box for the third largest, and so on.)

- [ ] 1. 0 to 1 year
- [ ] 2. 1 to 4 years
- [ ] 3. 5 to 9 years
- [ ] 4. 10 to 14 years
- [ ] 5. 15 to 19 years
- [ ] 6. 20 to 64 years
- [ ] 7. 65 or over

15. How many clients with a developmental disability does your agency/organization serve?

INSTRUCTIONS:

Please read definition of racial/ethnic categories (see front page) before beginning.

Complete the chart below for specific types of developmentally disabled clients served by race/ethnicity.

The sum of Rows 2 and 3 should equal to Row 1, and the sum of Rows 4 through 7 should equal to Row 3.

	Autism	Cerebral Palsy	Epilepsy	Mental Retardation	Multiple Diagnosis
Row 1 [ ] TOTAL DD CLIENTS SERVED					
Row 2 [ ] TOTAL WHITE (not of Hispanic Origin)					
Row 3 [ ] TOTAL MINORITY					
Row 4 [ ] American Indian or Alaskan Native					
Row 5 [ ] Asian or Pacific Islander					
Row 6 [ ] Black (not of Hispanic Origin)					
Row 7 [ ] Hispanic					

16. How do the largest number of minority clients come to the agency? (Check only one.)

- [ ] 1. Self referral
- [ ] 2. Family referral
- [ ] 3. Medical referral
- [ ] 4. Non-medical professional referral
- [ ] 5. Other agency referral
- [ ] 6. Case-finding & outreach
- [ ] 7. Schools
- [ ] 8. Courts
- [ ] 9. Other (specify) _____

17. How do the largest number of White clients come to the agency? (Check only one.)

- [ ] 1. Self referral
- [ ] 2. Family referral
- [ ] 3. Medical referral
- [ ] 4. Non-medical professional referral
- [ ] 5. Other agency referral
- [ ] 6. Case-finding & outreach
- [ ] 7. Schools
- [ ] 8. Courts
- [ ] 9. Other (specify) _____

18. Of the services categorized here, which three are most frequently provided by the agency to your clients who are developmentally disabled? (Place a '1' next to the most frequently provided service category, a '2' next to the second most frequently provided service, and a '3' next to the third.)

- [ ] 1. Identification (Diagnosis, evaluation, information & referral)
- [ ] 2. Direct services (Counseling, planning & coordination of services, social, sociological & legal services, court, follow along)
- [ ] 3. Treatment (Medical, dental, occupational therapy & other special treatment)
- [ ] 4. Education (Pre-school, school-age, adult, day care, education/training, health education)
- [ ] 5. Residential services (Domiciliary care, special living arrangement)
- [ ] 6. Employment (Job placement, training, sheltered, other)
- [ ] 7. Family/Program Support (Recreation, personal care, transportation)
- [ ] 8. Outreach Programs
- [ ] 9. Other (specify) _____

19. In what settings do the developmentally disabled clients, served by the agency, live?

INSTRUCTIONS:

Please read definition of racial/ethnic categories (see front page) before beginning.

Complete the chart below by race/ethnicity and the settings where the developmentally disabled clients live.

The sum of Rows 2 and 3 should equal to Row 1, and the sum of Rows 4 through Row 7 should equal to Row 3 in each particular setting.

	SETTING WHFRE DD CLIENTS LIVE		
	Own Home	Institution	Out of Home Community Placement
Row 1 [ ] TOTAL CLIENTS			
Row 2 [ ] TOTAL WHITE (not of Hispanic Origin)			
Row 3 [ ] TOTAL MINORITY			
Row 4 [ ] American Indian or Alaskan Native			
Row 5 [ ] Asian or Pacific Islander			
Row 6 [ ] Black (not of Hispanic Origin)			
Row 7 [ ] Hispanic			

20. Does your agency have an outreach program?

[ ] 1. Yes
[ ] 2. No

If no, proceed to Question #23.

21. If your agency has an outreach program, what is the principal purpose of the program? (Check only one.)

[ ] 1. Referral of clients for services
[ ] 2. Locating potential clients
[ ] 3. Distribution of information
[ ] 4. Community education and prevention
[ ] 5. All of the above
[ ] 6. Other (specify) _____

22. Within the outreach program, what is the method used to reach minorities and non-minorities?

INSTRUCTIONS:

Please read the definition of racial/ethnic categories (see front page) before you begin.

Complete the chart below by placing a check mark (✓) to the principal method used to reach clients for each racial/ethnic category.

	METHODS USED TO REACH MINORITY AND WHITE CLIENTS									
	Health Fairs	Leaflet Distribution	Parent Groups	Posters	Home Visits	Visits to Other Agencies	Circulating Mobile Units	Radio/TV Spots	Community Meetings	Other, Specify
WHITE (not of Hispanic Origin)										
MINORITY										
American Indian or Alaskan Native										
Asian or Pacific Islander										
Black (not of Hispanic Origin)										
Hispanic										

23. If the agency has no outreach program, what is the most important reason for not having one? (Check only one.)

- [ ] 1. Not budgeted
- [ ] 2. Too costly
- [ ] 3. Not sufficiently staffed
- [ ] 4. Waiting list already too long
- [ ] 5. Not needed, community already aware of services
- [ ] 6. The area to be served is too large
- [ ] 7. Did not think about it
- [ ] 8. Do not know how to set one up

24. As nearly as your agency can determine, do minority populations know about and use the services to the fullest extent possible?

- [ ] 1. Yes
- [ ] 2. No

25. If the answer to Question #24 is 'no,' as nearly as your agency can determine, what factors prevent minority populations from knowing about and using services? (Check all that apply.)

- [ ] 1. Language barrier
- [ ] 2. Lack of transportation
- [ ] 3. Lack of information about the agency
- [ ] 4. Families too involved in "survival issues"
- [ ] 5. Lack of communication between staff & parents
- [ ] 6. Agency hours don't meet clients needs
- [ ] 7. Cannot afford to pay agency fees
- [ ] 8. Other (describe) _____

26. Which of the following are included in your eligibility requirements? (Check all that apply.)

- [ ] 1. Income
- [ ] 2. Type of disability
- [ ] 3. Geographic location
- [ ] 4. Age
- [ ] 5. Sex
- [ ] 6. Marital status
- [ ] 7. Ethnic group
- [ ] 8. All of the above
- [ ] 9. No eligibility requirements

27. What is the length of time a client typically spends on the waiting list before receiving services? (Check only one.) NOTE: Services are those innumerated in Question #18.

- [ ] 1. We have no waiting list
- [ ] 2. 1 - 2 months
- [ ] 3. 3 - 6 months
- [ ] 4. 7 months to 1 year
- [ ] 5. More than 1 year

28. What is the distance (round trip) typically traveled by clients to receive services from your agency? (Check only one.)

- [ ] 1. Less than 10 miles
- [ ] 2. 11 - 30 miles
- [ ] 3. 31 - 50 miles
- [ ] 4. 51 - 100 miles
- [ ] 5. Over 100 miles

29. As nearly as the agency can determine, is any language other than English needed in order to serve the agency's clients?

- [ ] 1. Yes
- [ ] 2. No

30. If the answer to Question #29 is 'yes,' what language(s) are needed? (Check all that apply.)

- [ ] 1. Sign language
- [ ] 2. Spanish
- [ ] 3. Japanese
- [ ] 4. Chinese
- [ ] 5. Other (specify) _____

31. What language(s) other than English are spoken by agency staff? (Check all that apply.)

[ ] 1. None, English only
[ ] 2. Spanish
[ ] 3. Japanese
[ ] 4. Chinese
[ ] 5. Other (specify) _____

32. Are any materials describing agency programs and services available in languages other than English?

[ ] 1. Yes
[ ] 2. No

33. If the answer to Question #32 is 'yes,' in what language(s) are materials available? (Check all that apply.)

[ ] 1. Spanish
[ ] 2. Japanese
[ ] 3. Chinese
[ ] 4. Braille
[ ] 5. Other (specify) _____

SECTION IV: PARTICIPATION

34. Does the agency have a policy or decision-making board?

[ ] 1. Yes
[ ] 2. No

If your agency has no policy or decision making board, proceed to Question #37.

35. How many persons serve on the agency/organization's board?

INSTRUCTIONS:

Please read the definitions of racial/ethnic categories (see front page) before you begin.

Complete the chart below for board members by race/ethnicity. Distribute these figures as to whether the board member is developmentally disabled or not.

The sum of Rows 2 and 3 should equal to Row 1, and the sum of Rows 4 through 7 should equal to Row 3.

	DEVELOPMENTALLY DISABLED	NON DEVELOPMENTALLY DISABLED
Row 1 [ ] TOTAL #OF PERSONS ON BOARD		
Row 2 [ ] TOTAL WHITE (not of Hispanic Origin)		
Row 3 [ ] TOTAL MINORITY		
Row 4 [ ] American Indian or Alaskan Native		
Row 5 [ ] Asian or Pacific Islander		
Row 6 [ ] Black (not of Hispanic Origin)		
Row 7 [ ] Hispanic		

36. How are agency/organization's board members selected?

INSTRUCTIONS:

Please read the definitions of racial/ethnic categories (see front page) before you begin.

Complete the chart below for each racial/ethnic category, and methods by which they are selected for board membership.

The sum of Rows 2 and 3 should equal to Row 1, and the sum of Rows 4 through 7 should equal to Row 3.

	Elected by Community	Elected by Board Members	Appointed by Public Official	Elected by Member-ship	Other
Row 1 [ ] TOTAL BOARD MEMBERS					
Row 2 [ ] TOTAL WHITE (not of Hispanic Origin)					
Row 3 [ ] TOTAL MINORITY					
Row 4 [ ] American Indian or Alaskan Native					
Row 5 [ ] Asian or Pacific Islander					
Row 6 [ ] Black (not of Hispanic Origin)					
Row 7 [ ] Hispanic					

37. In which way do the largest number of clients participate in the implementation and delivery of the agency's programs and services? (Check only one.)

[ ] 1. Outreach activities
[ ] 2. Serve on committees, groups or councils which monitor agency's performance
[ ] 3. Inform agency of their needs through their worker
[ ] 4. Agency volunteer
[ ] 5. Seek and/or contribute funds
[ ] 6. Not involved
[ ] 7. Other (specify)

_____

38. In which way do the largest number of clients participate in the planning of the agency's programs and services? (Check only one.)

- [ ] 1. Member of planning board or committee
- [ ] 2. Participates in parent/ social worker meetings
- [ ] 3. Member of advocacy group
- [ ] 4. Suggestions made to agency via case worker
- [ ] 5. Not involved
- [ ] 6. Other (specify)

_____

39. How much impact do each of the following categories have on planning, policy formation and decision-making?

INSTRUCTIONS:

Complete the chart below by placing a check (✓) mark in each box with respect to the degree of impact each category has on the agency's planning, policy formation and decision-making.

	GREAT DEAL	SOME	NONE
Board Members			
Direct Service Staff			
Administrative Staff			
Volunteers			
Other (specify)			

SECTION V: ADDITIONAL COMMENTS

Please comment on what your agency/organization sees as the unmet service needs of the minority developmentally disabled population in the catchment area.

Also, feel free to make comments regarding this questionnaire, or elaborate on responses to questions asked.

Thank you for your time and cooperation.

2/79

APPENDIX G

QUESTIONS POSED AT NATIONWIDE MEETINGS OF PARENT/CONSUMERS AND SERVICE PROVIDERS, AND SAMPLES OF LETTERS REQUESTING ASSISTANCE IN IDENTIFYING PARENTS AND DD CONSUMERS

QUESTIONS FOR DISCUSSION
AT NATIONWIDE MEETINGS

At the nationwide meetings we discussed two sets of questions -- one addressed to parents/consumers, and the other addressed to service providers.

Parent/Consumer Questions

1. Do you feel the services you get are adequate?
2. How did you go about finding out about those services you now use?
3. What kinds of barriers have you encountered in getting services?
4. What kinds of barriers have you encountered in being involved on boards, committees, etc?
5. How many of you serve on boards and/or committees?
6. How did you find out about these committees?
7. How do you feel about your role on the board? For example, do you feel you are listened to? Are your recommendations followed?
8. If you do not serve on a board or committee, how do you make your desires or comments regarding services known?
9. How many of you know a minority person involved in developmental disabilities?
10. What position does this person hold in the agency where they work?

Service Provider Questions

1. Do you perceive that the minority developmentally disabled person has needs which warrant a different approach to service delivery and outreach?
2. Do you feel you need minorities on your staff who reflect the population served?
3. Do you feel you're meeting the needs of the minority community?
4. Where in your agency's structure is the point where minorities can have the greatest impact on the quality of services delivered?

5. On what subjects or areas would you most want to have minority input?

6. Describe your outreach program approach, who does it? Cases discovered as a result of outreach.

7. What is your referral process and what kind of follow-up is done?

8. Do you know the number of minorities on your board or employed as staff members? For those who are staff members, what are their positions?

9. What kinds of support are available for parents to attend meetings? (i.e., transportation services, etc.)

10. What service agencies does your agency interact with?

11. Are any of these minority?

NEW
DIMENSIONS IN COMMUNITY SERVICE, INC.

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M.S.W.

LETTER TO DIRECTORS OF HEW REGIONAL OFFICES OF DEVELOPMENTAL DISABILITIES

January 21, 1977

Dear

This letter is in follow-up to our recent meeting in Washington where projects of national significance were discussed. Per that meeting, this will solicit your support of the goals and objectives of the nationwide study designed to assess the quantity and quality of minority participation in the developmental disabilities movement.

Your support is specifically needed as a means for encouraging the participation of provider agencies and developmental disabilities councils in the study. Their participation is sought in two ways:

1. Attendance at service provider sessions scheduled as part of the series of meetings in various cities throughout the country. These sessions are in the afternoon (2 - 4 p.m.). A listing of locations and dates for the meetings is attached. The agenda for these sessions include a detailed discussion of the study, exchange of information among provider agencies, and a brief review of parent/consumer comments solicited during the morning session.

2. Response to survey questionnaires.

The benefits to developmental disabilities provider agencies, developmental disabilities councils and advocacy groups are many. Although our project does not provide direct services to parents or consumers, we are nevertheless, being overwhelmed with requests from them to participate in the meetings. We believe the process being used to identify parents is an important factor in their positive response. This process can be adaptable for use by those seeking to expand and/or improve minority participation.

A private non-profit, tax exempt organization

Fosters participation in solutions to problems affecting health, education, economic and social well-being of the individual and family through self-help, self-determination and community awareness

Recommendations from Parents and Consumers to Service Providers

- Agencies should include more minorities in policy, decision-making roles in the service delivery system.

- Agencies should improve outreach efforts by using staff, including minorities, who are sensitive to the needs of the disabled and their parents.

- Agencies should encourage home visits by staff who are sensitive to the culture and life-styles of the clients being served or evaluated. This is especially needed before a child is placed in special education classes, since staff and teachers should understand the child's family environment. Professionals should also make follow-up visits to homes of the developmentally disabled at least once a month to determine if the parents are satisfied with the service they received and whether they have additional needs or ideas for improving services. This approach is one way of insuring the latter's input in planning DD programs.

- Professionals could work to organize a small group of parents to act as a liaison between the agency and individuals needing services.

- Agencies should establish awareness programs to advertise their services through pamphlets, letters, flyers, and posters written in easily understood language, in both English and other languages.

- Agencies should provide a "hotline" for parents and consumers in need of special or emergency services. They should inform the affected community of its availability through materials and information distributed in a variety of different outlets -- schools, churches, food stamp outlets, barber and beauty shops, public housing projects, radio and TV spot announcements, etc.

- Agencies should help educators who work with disabled children become more sensitive to the needs and feelings of these children and adults. Many educators need this awareness, since they tend to see handicapped children as someone they can easily push around or hide away out of sight.

- Agencies should establish requried in-service training programs to sensitize staff to better understand how the disabled and their parents feel. Agency receptionists, secretaries, and volunteers should be part of this training, since they are the first contact parents and consumers encounter in the DD system. This training should help staffers better deal with the retarded, and better understand, respect, and communicate with parents with differing culture and value systems.

- Agencies should keep abreast of new regulations and trends affecting the disabled so they can modify old rules and policies to meet new standards.

- Agencies should coordinate with other agencies of the disabled to eliminate duplication and avoid the delays some experience in finding and using services, due to confused definitions and agency jurisdictions.

- Agencies should provide special services for parents and health impaired children, such as transportation, supportive services, extra counseling after regular work hours, tutorial services, employment resources, etc.

- Agencies should maintain a referral list of physicians and dentists who are experienced in treating developmentally disabled children, so they can be readily referred to them when they are ill or have dental problems.

- Agencies should develop and offer refresher courses for physicians on how to diagnose disabilities as early as possible, counsel the family, and make the appropriate agency referrals. The agencies should also provide physicians, especially family practitioners and pediatricians, with an updated listing of services available for the developmentally disabled.

Recommendations From Parents and Consumers to Parents

- Parents should get involved and participate more actively in a variety of DD activities, including boards and committees.

- Parents should become more aware of who is funding programs, and to what agencies.

- Parents should educate themselves and inform other parents about DD programs in their community. They can organize themselves and become advocates for themselves and their children.

- Parents should form advocacy groups and become active in generating good DD legislation or preventing bad legislation from being passed.

- Parents should be more trusting and respectful of service providers.

- Parents should become involved in each step of their child's examination and diagnosis. They should feel free to ask questions.

- Parents should help educate parents who have normal children in a classroom with children who are developmentally disabled, so that their children understand that a disabled child is a human being, and is hurt when others pick on him or call him names. Parents should seek the help of the principal or teachers in bringing about this improved situation.

Recommendations From Parents and Consumers to DHEW

- DHEW should provide more finances for services, such as respite care, residential/day care homes and facilities for different age groups, and more recreational services.

- DHEW should mandate that educational systems include nutrition classes as a way of preventing some developmental disabilities.

- DHEW should require that the programs it funds offer complete services to the family, as well as the developmentally disabled, since a developmentally disabled child concerns the entire family.

- DHEW should initiate a bill of rights for the handicapped.

- DHEW should mandate more intensive public education programs.

- DHEW should examine the personnel hiring practices of agencies and develop mandates or guidelines instructing agencies serving minorities who are developmentally disabled to have minorities on their staff and on their boards.

- DHEW should encourage local TV and radio stations to increase public service announcements on the availability of DD programs, and encourage the stations to schedule these during the day and evening when people are more likely to be viewing or listening.

- DHEW should better monitor and evaluate DD programs to ensure that the minority disabled are being served.

- DHEW should devise a system, such as a board or committee, so that parents can register their complaints about the educational system.

Other General Recommendations From Parents and Consumers

- There should be life insurance available for the mentally retarded.

- Low income or the unemployed disabled and parents of the disabled should receive reimbursement for transportation, baby sitting, child care, and meals when they attend meetings, to encourage them to participate. Possibly, they might also get an hourly or per diem stipend.

- Teenagers and college-age persons should be exposed to information about handicaps and developmental disabilities, so they will be more understanding.

4) Recommendations on Data and Research Needs. The following recommendations are being made based on research and data gaps identified from the survey, literature review, and comments of parents and consumers and service providers. There is the need for the following data:

- A survey of consumers' views on the nature and extent of services received and unmet needs.
- A national study to determine DD prevalence rates among various ethnic groups. Such a study might be undertaken for instance, by the National Center for Health Statistics. The information would be made available to DD Councils for use in their planning process.
- An assessment of the needs of the disabled not served by an agency.
- An assessment of the drop-out rate of clients from agencies and the reasons.
- The development of a federally based data-management system in the DD field.

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APPENDIX A

RESOURCES DEVELOPED BY THE PROJECT

1. Estimates of the Number of Minority Developmentally Disabled Persons Using State Prevalence Rates and 1970 Census Figures: A Working Paper

2. Preliminary Report on Number of Minority Developmentally Disabled Persons served by Selected State Agencies

3. Factors Affecting Minority Participation in the Delivery of Services to the Developmentally Disabled: A Review and Critique of the Literature

4. The Delivery of Developmental Disability Services to Minority Persons: A Two-Fold Perspective

5. A Select List of Minority Persons Interested in Services to Minority Developmentally Disabled

6. A Select List of Minority Professionals Concerned with Services to the Developmentally Disabled

7. Volume I, Educational Abstract: A Selected Annotated Bibliography on Minority Populations and Developmental Disabilities

8. Volume II, Psychological Abstract: A Selected Annotated Bibliography on Minority Populations and Developmental Disabilities

9. Volume III, Psychological Abstract: A Selected Annotated Bibliography on Minority Populations and Developmental Disabilities

10. Volume IV, Exceptional Child Abstract: A Selected Annotated Bibliography on Minority Populations and Developmental Disabilities

11. Volume V, Dissertation Abstract: A Selected Annotated Bibliography on Minority Populations and Developmental Disabilities

12. Volume VI, Studies in Health and Related Services Undertaken by State and Federal Entities: A Selected Annotated Bibliography

13. A Compendium of Conversations with Minority Parents and Consumers: Transcripts from the Nationwide Study Meetings on Minority Participation in the Developmental Disabilities Movement

14. A Compendium of Conversations with Service Providers: Transcripts from the Nationwide Study Meetings on Minority Participation in the Developmental Disabilities Movement

15. A Nationwide Listing of 5000 Service Provider Agencies

16. An Educational Manual on Developmental Disabilities

APPENDIX B

WRITTEN AND ORAL PRESENTATIONS BY PROJECT STAFF

Written Presentations

1. A Report on the Preliminary Findings of the Nationwide Study on Minority Participation in the Developmental Disabilities Movement, published in Abstracts in Social Work

   Presented to: The National Conference on Social Welfare, Los Angeles, California -- May, 1978

2. Reaching Out to Serve the Minority Developmentally Disabled Citizen, published by Research and Training Center in Mental Retardation -- Texas Tech University
   Presented to: Conference on Implementation of Developmental Disabilities Protection and Advocacy Systems, Cherry Hill, New Jersey -- December, 1977

3. Statement on California's 1979 State Plan for Developmental Disability Services and Facilities Construction Program

   Presented to: Public Hearing on California's 1979 State Developmental Disabilities Plan, San Francisco, California -- September, 1978

4. Statement on California's 1978 State Plan for Developmental Disabilities

   Presented to: Public Hearing on California's 1978 State Developmental Disabilities Plan, San Francisco, California -- September, 1977

5. Towards Understanding the Need for Minority Participation in the Developmental Disabilities Movement: The Nationwide Study

   Presented to: The President's Committee on Mental Retardation, A National Multi-Cultural Seminar on Mental Retardation Among Minority Disadvantaged Populations, and the Department of Special Education, Norfolk State College, Norfolk, Virginia -- October, 1977

6. Implementing Habiiitation Services for Minority Clients

   Presented to: The California State Developmental Disabilities Council Meeting, San Francisco, California -- November, 1978

7. The Importance of Culture in Serving the Mentally Retarded

   Presented to: A Seminar on Mental Retardation, University of California at Los Angeles, Neuropsychiatric Institute -- January, February, 1979

8. Statement on Services to the Developmentally Disabled

   Presented to: Health and Environmental Committee
   San Francisco Board of Supervisors
   January, 1979.

ral Presentations

1. Discussion on Cultural Differences of Minority Clients which Impact on the Treatment Process

   Presented to: In-service Training Session at Golden Gate Regional Center, San Francisco, California -- January, 1978

2. Needs of the Hispanic Developmentally Disabled

   Presented to: Developmental Disabilities: A Multi-Cultural Perspective, Co-sponsored by the Golden Gate Regional Center, San Francisco, and Continuing Education in Nursing, University of California at San Francisco -- May, 1978

3. Needs of the Hispanic Developmentally Disabled Population

   Presented to: Tri-Counties Regional Center's Fifth Annual Scientific Symposium on Developmental Disabilities, Santa Barbara, California -- April, 1978

4. Preliminary Findings of the Nationwide Study on Minority Participation in the Developmental Disabilities Movement

   Presented to: Project Impact Training Institute of the National Association for Retarded Citizens, Full Citizenship for the Low-Income Mentally Retarded, San Francisco, California -- August, 1977

5. Estimates of the Number of Developmentally Disabled Minorities in California Using Prevalence Rates and Census Figures

   Presented to: The San Francisco Developmental Disabilities Council, San Francisco, California -- November, 1977

6. Discussion on Counseling and Serving the Minority Disabled Client

   Presented to: In-service Training Session at the Department of Social Services, Developmental Disabilities Unit, San Francisco, California -- October, 1977

7. Unique Problems of Handicapped Minorities

   Presented to: The White House Conference on Handicapped Individuals, Washington, DC -- May, 1977

8. Issues in Service Delivery to Minorities

   Presented to: The California Conference on Handicapped Individuals, Los Angeles, California -- November, 1976

9. Minorities and Epilepsy

   Presented to: Workshop on Cultural and Minority Groups, Commission for the Control of Epilepsy and Its Consequences, Washington, DC -- May, 1977

10. Preliminary Findings of the Nationwide Study

    Presented to: Joint Developmental Services Liaison Committee, Sacramento, California -- August, 1978

11. Needs of Minority Disabled Children

    Presented to: Black Child Development Institute: Regional Conference, Los Angeles, California -- March, 1977

12. Presentation of Goals, Objectives and Methodology of the Nationwide Study

    Presented to: Region VI Developmental Disabilities Technical Assistance Services, Dallas, Texas -- March, 1977

13. Presentation of Goals, Objectives and Methodology of the Nationwide Study

    Presented to: Region VIII Developmental Disabilities Technical Assistance Services, Logan, Utah -- February, 1977

14. Culture and Counseling the Developmentally Disabled Client in a Psychiatric Setting

Presented to: In-service Training Session at McAuley Psychiatric Institute, St. Mary's Hospital, San Francisco, California -- March, 1979

15. Public Law 94-142 -- Education for all Handicapped Children, "What the Minority Community Should Know"

Presented to: SEARCH for the Handicapped, KPIX Channel 5 Television: "All Together Now", San Francisco, California -- 1978

APPENDIX C

CHRONOLOGY OF SUBMISSIONS AND MEETINGS
WITH DDO STAFF IN WASHINGTON, D.C.

1976

October:	New Dimensions in Community Service, Inc. (NDCS) received the grant to implement a nationwide study on minority participation in the developmental disabilities movement (general design for survey included with the grant proposal).
November-December:	Planning for Nationwide Meetings

1977

January-February-March:	Meetings held
April-May-June:	Preparation of reports on meetings and development of survey designs and instruments (client/consumer and service provider)
July 15:	Submission to HEW of specifics on the design and instrument for the client/consumer survey
August 22:	Submission to HEW of draft of the design and instrument for the service provider survey
September:	Submission to HEW of final design and survey for the service provider survey
October 13:	Project Director and Research Consultant met in Washington with representatives from the Office of Program Reporting and Evaluation (OPRE), and the Developmental Disabilities Office (DDO). Meeting focused on whether the survey was meant to be exploratory or controlled research
November-December:	Materials submitted responding to issues raised in October 13 meeting
December:	DDO/OPRE submitted materials to OMB for clearance

1978

January:	DDO advised project that an official from DHEW had recalled the materials from OMB
February-March:	Submissions in response to questions raised by DHEW official
June:	Phone calls between project and DDO attempting to clarify additional questions raised by DHEW
	Request for one (1) year extension submitted by NDCS (due to delay of clearance)
July 24-25:	Project Director and Consultants met in Washington with representatives from OPRE and DDO. Decision made to implement study in a two-stage fashion; the service provider portion first, the client/ consumer portion, second
August 31:	Submission of revised Phase One (service provider) design based upon discussion in July 24-25 meetings
October:	Request by DHEW for clarification on August submission. Addendum materials forwarded by project
November:	Request by DHEW to integrate addendum materials with the August 31st submission
	Addendum materials integrated and resubmitted by project
December:	Submission of draft materials on Phase Two (client/ consumer survey design)

1979

January:	Review of materials by DDO/OPRE
February 26:	Official notification of OMB clearance of the Service Provider Design
March:	Service provider questionnaire disseminated to survey sample

March 14:	Project staff and Consultant met in Washington with OPRE and DDO representatives to discuss progress of service provider survey and plans for the client/ consumer "pilot" survey
June:	Submission of a pre-test client/consumer survey design
July:	NDCS requested withdrawal of the consumer/client survey at this time due to the delay in the service provider clearance process. It would not be possible to complete this process within the remaining time limits of the grant (September 30th)
August-Sept.-October:	Writing of report
November:	Submission of report for review and comment
December-January:	Dissemination of report and close-out of project

APPENDIX D

LIMITATIONS OF THE SURVEY

Limitations of the Survey

Although the survey provided much valuable data on the nature and scope of minority participation in DD services, there were some limitations which must be noted. The first and foremost limitation was that about half of the agencies receiving questionnaires either did not respond or returned questionnaires with so little information that they were not included in our data analysis. A total of 844 agencies (out of 1,500 to which questionnaires were sent) acknowledged receipt of the questionnaire, either by mail or by phone, and 732 of these agencies included sufficient information for their questionnaires to be included in the data analysis. This non-response rate is a factor in all survey research, particularly when the popular mail questionnaire is used, where a low response rate is typical. The lower the response rate, the higher the probability of bias due to differences between non-respondents and respondents. For this reason, we carried out a series of follow-up procedures in order to achieve a high response rate and, in the process, agencies stated many factors that prevented them from responding.* These factors may be relevant to the assessment of bias (e.g., agencies with few staff members may be more or less likely to have their records available for inspection) and so we include some of them here.

Factors limiting the response rate. Based upon respondents' remarks in Section V of the questionnaire and correspondence from those who gave their reasons for declining to participate, we found that most did not respond for one or more of the following reasons:

1) Unavailable or inaccessible data:

   - The data were unavailable
   - The data were only available in fragmented form
   - The data were unavailable at the time, although it will be available later

*Follow-up included telephoning, mailgrams, 3 additional mailings of the questionnaire to non-respondents.

- regulations (state or local) do not require that such information be maintained

- the agency/organization did not have the computer capability to retrieve the data

2) The agency does not serve the disabled or minorities:

- The organization did not tabulate data on the disabled as a separate group, since the developmentally disabled were not the primary target population

- There are no minorities in the service area

- The questionnaire should be referred to a more appropriate agency

- The agency/organization is no longer serving the disabled

3) The agency did not have the time, staff, or funds to complete the survey:

- Staff was unavailable to complete the survey

- The questionnaire required too much time

- There are too many surveys and too much duplication of information requested

4) Other reasons:

- The agency felt the questionnaire was designed for a direct service provider

- The agency/organization doubts the value of the survey

- The agency felt the survey did not have the proper clearance from an appropriate source

- The agency felt that DHEW, the Rehabilitation Services Administration or Office for Civil Rights had data similar to what we sought

We have been unable to detect any associations between nonresponding and agency characteristics (although we did not do a systematic study of this issue). For example, some large agencies indicated that the questionnaires would be more applicable to small service providers, while some small agencies stated that only a large agency would have the data in the specicity we required.

A second limitation is that the actual number of agencies in the DD field may be more or less than the number we identified, since our mail response indicated that a number of agencies had gone out of business or no longer served the disabled. On the other hand, this number may be greater because of agencies not being included in any listing.

A third limitation is the possibility of duplicate reports or overlapping reports in the number of clients served by responding agencies/organizations. This may be a problem because the consumer receives services from a myriad of state, local, federal, and other agencies, which include hospitals, sheltered workshops, Departments of Rehabilitation, associations for retarded citizens, day care centers, etc. However, since our sample represents about 3 percent of the identified agency universe, the problem of duplication or overlap is probably not serious.

Finally, the study is limited in that there is no systematic input from the disabled not served by any agency.

Because of these limitations, the present study should be regarded as only a partial attack on the problem of assessing the state of the art in the developmental disabilities movement and minority participation in it. However, since this is a field where data are sorely lacking, the data we have gathered should be helpful in furthering understanding of minority participation in the DD field. In addition, since the survey includes data on the non-minority disabled, it should increase understanding of the DD field generally.

Limitations of Nationwide Meetings

At the nationwide meetings we discussed two sets of questions -- one addressed to parents/consumers, and the other addressed to service providers. The questions are given in Appendix G.

Second, through our implementation approach, several projects which have developed successful outreach methods have been identified. By participating in the meetings, agencies seeking to improve their outreach can interact with representatives of these projects and improve their outreach efforts.

Third, by participating in the meetings, agencies can impact directly on the study. Our questionnaire has not been finalized and through meetings with provider agencies, we will obtain their input on what questions to ask and which areas to examine.

Fourth, the study, through the parent/consumer meetings, will identify for provider agencies and developmental disabilities councils, those cultural and ethnic related issues which impact (positively and negatively) on minority population participation.

And lastly, the end product of the study, a plan for use by service providers and developmental disabilities councils on how to improve and expand minority participation, should prove to be an invaluable resource.

As I stated during my presentation at the Washington meeting, the minority developmentally disabled population is a "minority within a minority." Their special needs must be identified and addressed if the service delivery system is to be equitable. While addressing the issue of meeting their special needs, some assessment of their current involvement is necessary. This is what our study seeks to do.

Thank you in advance for your support.

Sincerely,

Beverley, J. Morgan,
Project Director

BJM:et

Encl.

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LETTER TO PARENTS AND CONSUMERS

Dear

You have been recommended for participation in a nationwide study on minority involvement in developmental disabilities.

Your attendance is therefore requested at a meeting scheduled for:

Date:
Time:
Location:

The meeting is part of the national study being undertaken by New Dimensions in Community Service, Inc., a San Francisco-based human services organization. The study is funded by the Department of Health, Education, and Welfare, Office of Human Development, Developmental Disabilities Office in Washington, DC.

The meeting will seek your input on the following subjects:

1. Your assessment of the adequacy of services offered to the developmentally disabled and the need for additional services.

2. Identification of key issues involving developmental disability service delivery where minority input is essential.

3. Identification of barriers to minority participation in decision-making regarding service delivery, planning for program expansion, etc.

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4. The nature of your involvement with developmental disabilities, i.e., your participation on developmental disability councils, membership in associations, etc.

5. Recommendations on how agencies, organizations, state and federal departments can improve or expand minority participation.

To facilitate discussion and exchange of ideas, participation is being limited to 35 persons. Therefore, please return the enclosed card at your earliest convenience. The rate for reimbursement to parents and consumers for per diem and travel is listed below.

I look forward to your participation.

Sincerely,

Beverley J. Morgan,
Project Director

BJM:et

Encl.

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LETTER SOLICITING SUPPORT AND NAMES OF CONSUMERS/PARENTS FROM PROVIDER AGENCIES

Dear

A nationwide study on minority (Asian, Black, Native American, and Spanish-speaking) participation in the developmental disabilities movement is being undertaken by New Dimensions in Community Service, Inc., a human service organization. This two-year study, funded by the Office of Human Development, Developmental Disabilities Office, Department of Health, Education, and Welfare, includes a survey of developmental disability (DD) agencies and services. The study will result in the development of a plan for use by service providers to expand and improve minority participation. Some conditions which are defined as DD include mental retardation, autism, cerebral palsy, and epilepsy.

The first major task includes hosting one-day meetings in 14 cities throughout the country. The conferences are designed to obtain input from minority persons (particularly parents and consumers) on the nature and extent of minority involvement in developmental disabilities in their region.

Your assistance is requested in compiling a list of minority DD persons, parents of DD children, and concerned professionals to participate in a two-hour (10 a.m. - 12 noon) morning meeting. If for reasons of confidentiality you are unable to send us names of clients, we would appreciate your distributing information on the meeting to your minority consumers and encouraging their participation. Because of your involvement in service delivery, your attendance is requested at the afternoon session (2 - 4 p.m.).

Both sessions are limited to 35 participants. Therefore, please indicate your intent to attend on the enclosed card and return it as soon as possible. Also, may we receive your list of minority parents and consumers at your earliest convenience.

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The meeting is scheduled as follows:

Date:

Time: 10 a.m. - 12 noon (Morning Session: Parents/Consumers)
2 - 4 p.m. (Afternoon Session: Service Providers)

Place:

Please note that limited funds are available for minority parents to cover approved costs for attending the meeting.

A summary of the project is also enclosed for your review.

Your assistance and cooperation are greatly appreciated.

Sincerely,

Beverley J. Morgan,
Project Director

BJM:et

Encl.

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KATHRYN WITCHER
M.S.W.

November 23, 1976

LETTER TO DEVELOPMENTAL DISABILITIES COUNCIL CHAIRPERSONS AND STAFF DIRECTORS OR COORDINATORS

Dear

A nationwide study of Minority (Asian, Black, Native American, and Spanish-Speaking) participation in the developmental disabilities movement is being undertaken by New Dimensions in Community Service, Inc., a human service organization based in San Francisco. This two-year study is funded by the Office of Human Development, Developmental Disabilities Office, Department of Health, Education, and Welfare. A summary of the project is enclosed.

As chairperson of your State's Developmental Disability Council, your support of the project is crucial. The project seeks to not only determine the quantity and quality of minority participation, but also to develop a plan for increased and improved participation.

The first major task includes hosting one-day conferences in 14 cities throughout the country. The conferences are designed to obtain input from minority persons (particularly parents and consumers) on the nature and extent of minority involvement in developmental disabilities in their region. Service providers, developmental disability councils, associations and organizations will also be asked to participate. Parents and consumers will meet in a morning session. Representatives of service providers, developmental disability councils, associations and organizations will meet in an afternoon session. Each session will be limited to 35 participants to facilitate discussion and exchange of ideas.

The conference is scheduled for in your region and will be held in . You will receive notification of the exact time, date, and meeting site.

Your assistance is requested in compiling a list of minority developmentally disabled persons, parents of developmentally disabled children, and concerned professionals to participate in the conference. Please note that we have limited funds for travel reimbursement to parents and consumers. Therefore, please indicate

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on your list of possible participants, those individuals who will need this assistance.

Additionally, any assistance you could give in providing the following information on your State is appreciated.

1. List of social service agencies serving the developmentally disabled.

2. Contact person(s) within the special education departments of boards of education.

3. Contact person(s) within State rehabilitation departments.

I look forward to receiving your list at your earliest convenience. Please let me know if additional information is needed.

Your assistance and cooperation are greatly appreciated.

Sincerely,

Beverley J. Morgan

Beverley J. Morgan,
Project Director

BJM:et

Encl.

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M.S.W.

(LETTER TO MEMBERS OF PRESIDENT'S COMMITTEE ON MENTAL RETARDATION.)

In October 1976, the Department of Health, Education and Welfare, Office of Human Development, Developmental Disabilities Office, awarded a grant to New Dimensions in Community Service, Inc., for the purpose of undertaking a national study of minority (Asian, Black, Native-American and Spanish-Speaking) participation in the developmental disabilities movement. A summary of the project is enclosed for your review.

In order to interpret the objectives of the project and obtain the cooperation of service providers (both public and private) and consumers in the study, a series of small conferences are scheduled throughout the country.

The meetings are designed to seek input from consumers/parents on the following subjects:

1. Their assessment of the adequacy of services offered to the developmentally disabled and the need for additional services.

2. Identification of key issues involving developmental disability service delivery where minority input is essential.

3. Identification of barriers to minority participation in decision-making regarding service delivery, planning for program expansion, etc.

4. The nature of their involvement with developmental disabilities; i.e., their participation on developmental disability councils, membership in associations, etc.

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5. Recommendations on how agencies, organizations, state and federal departments can improve or expand minority participation.

And from the providers as follows:

1. The need for minority participation in developmental disability service delivery and planning.

2. Reasons for success or failure of efforts to involve minorities.

3. Barriers to minority participation.

4. Service needs of the developmentally disabled minority person.

The schedule for these meetings are as follows:

Phoenix, Arizona--Saturday, January 29, 1977--Phoenix Indian Center, 4025 North 2nd Street, Phoenix

Albuquerque, New Mexico--Tuesday, February 15, 1977--Heights Community Center, 823 Buena Vista, SE, Albuquerque

Dallas, Texas--Thursday, February 17, 1977--Association for Retarded Citizens, 2114 Anson Road, Dallas

New Orleans, Louisiana--Saturday, February 19, 1977--Billie Padel Building, Recreation Room, 1771 Nashville Avenue, New Orleans

Rapid City, South Dakota--Saturday, February 26, 1977--Howard Johnson Motorlodg 2211 Lacrosse, Rapid City

Kansas City, Missouri--Tuesday, March 8, 1977--Kansas City Regional Center, 610 East 22nd Street, Kansas City

Nashville, Tennessee--Thursday, March 10, 1977--Meharry Medical College, Nashville

Atlanta, Georgia--Saturday, March 12, 1977--DHEW Region IV Building, Room 222, 50 Seventh Street, NE, Atlanta

Chicago, Illinois--Saturday, March 26, 1977--Not Yet Determined

Philadelphia, Pennsylvania--Tuesday, March 29, 1977--Mezzanie Conference Room, Gateway Building, 3535 Market Street, Philadelphia

Washington, D.C.--Thursday, March 31, 1977--Martin Luther King Library, Washington, D.C.

As a member of the President's Committee on Mental Retardation, we would welcome your participation at the meetings if your schedule permits. We will meet with minority consumers and professionals in the morning from 10 a.m. to 12 noon and with service providers from 2 p.m. to 4 p.m.

If you have further questions, please do not hesitate to contact me or the Project Director, Ms. Beverley Morgan.

Sincerely yours,

Naomi T. Gray
Project Supervisor

NTG/shk

Enclosure

APPENDIX H

REGIONAL ESTIMATES

To obtain estimates of DD movement variables for the country as a whole, the regional estimates of these variables were multiplied by weights and then averaged, as described in Appendix E. The demographic data and sample statistics used in computing these weights are shown in Table H1. These data highlight the regional differences in the number of agencies, the number of minority disabled clients, and the weights used to average regional estimates.

An important finding contained in Table H1 concerns the number of disabled persons served by agencies, that is, the number of clients, and the relation of this number to the number of disabled persons estimated for each of the ten regions. We estimated the number of disabled clients by using the data from the questionnaire item asking agencies to report this number. We first computed the median number of clients per agency for each region, and then we multiplied this median by the number of agencies that we identified in the universe for each region. This product gives the estimated number of clients for each region. We also expressed this number of clients as a proportion of the estimated number of disabled persons per region. As can be seen in the Table, the percentage of persons who are clients of some agency varies from just 5% in Region VI to 33% in Region VIII with an average of about 16% nationally.

As might have been expected, the proportion of minority clients correlates positively across regions with the proportion of minority persons living in the region ($r=0.84$).

In Table H2 we present, for each region and for the nation as a whole, the percentage distribution of responses to each questionnaire item.

TABLE H1

RELEVANT DEMOGRAPHIC AND SAMPLE PARAMETERS

VARIABLE	REGIONS I	II	III	IV	V	VI	VII	VIII	IX	X	TOTAL
1. Total Population in '000	11,842	25,405	23,413	31,766	44,058	20,336	11,231	5,576	22,982	6,513	209,244
2. Minority Population in'000	621	4,943	3,581	7,548	4,821	6,367	817	545	6,367	391	35,001
(a) Percentage of Minorities	5	19	15	24	11	31	7	10	28	6	17
3. Number of Identified Agencies (N_i)	1,663	778	3,297	5,022	4,550	927	2,397	1,772	2,643	762	23,817
4. Number of Agencies in Sample	[illegible]	27	91	198	103	53	51	41	115	21	732
5. Estimated Number of DD Persons in '000	562	1,120	1,364	1,297	1,611	1,056	538	249	1,473	227	8,499
6. Estimated Number of DD Persons Served by Agencies (i.e., DD Clients) in '000	97	123	180	399	298	48	134	82	145	40	1,546
(a) Percentage of DD Clients Who are Minority Persons	9	12	10	39	4	41	3	17	24	8	21
7. Percentage of DD Persons Who are Clients of Some Agency	17	11	13	31	19	5	25	33	10	18	16
8. Weights Used in Averaging Regional Estimates to get the National Estimate ($W_i = N_i / \Sigma N_i$)	.07	.03	.14	.21	.19	.04	.10	.07	.11	.03	——

For each item, Chi-square tests of contingency were used to decide whether differences among the 10 regional percentage distributions were statistically significant (a 5% level of significance was adopted). The ordering of the items in Table H2 corresponds to the ordering on the questionnaire which was included in Appendix F.

TABLE H2

Summary of responses to questionnaire items for each region, for the pooled (unweighted) sample, for the weighted sample, for the state agencies, and for the combined sample. All numbers in the table are percentages. (Note: The percentages for a variable may sum to less than 100 when not all values of the variable are shown -- for example, the value "Other" is always omitted. Also, they may sum to more than 100 when multiple responses are allowed.

VARIABLE/VALUE	REGIONS										Regional Differences Significant?	Response Percentage	National Estimate
	I	II	III	IV	V	VI	VII	VIII	IX	X			
Type of agency											Yes	99	
State government	34	4	19	33	16	43	18	15	19	29			25
Local government	3	4	15	19	28	8	8	25	19	19			17
Private non-profit	56	85	42	36	49	43	53	45	50	38			46
Private profit	3	4	11	2	6	2	2	5	4	10			5
Other	3	4	13	10	1	4	18	10	14	5			7
Number of years serving DD											Yes	91	
Under 5 years	10	16	10	16	4	4	21	18	22	21			14
6 to 10 years	28	4	24	30	28	38	32	20	22	37			27
Over 10 years	62	80	67	55	67	58	47	62	56	42			60
Largest source of income											Yes	97	
Federal government	16	4	23	39	17	43	38	31	18	48			27
State government	45	60	43	37	34	45	31	44	40	43			39
Local government	10	7	11	6	29	2	6	10	16	5			13
Foundations and other private groups	3	0	1	1	2	2	0	0	3	0			1

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Largest source of income (cont'd)													
United Way and other voluntary fund-raising sources	7	7	8	8	6	6	10	8	4	0			7
Membership fees	0	0	0	0	0	0	0	0	3	0			0
Client fees	13	18	6	4	4	0	8	5	4	5			6
Other	7	4	8	5	8	2	6	3	11	0			7
Annual budget for DD services											Yes	80	
Under $100,000	42	12	40	39	34	38	40	40	51	50			40
$100,001 to $500,000	23	28	33	38	39	25	27	27	21	28			31
Over $500,000	35	60	27	23	28	38	33	23	29	22			29
Population in catchment area											Yes	90	
Under 49,000	20	13	24	35	40	30	39	48	11	16			29
49,001 to 100,000	10	17	12	18	28	26	18	11	10	16			17
100,001 to 500,000	40	17	39	31	15	17	18	22	30	53			27
Over 500,000	30	52	25	16	19	26	25	19	50	16			26
Proportion of minority population in catchment area											Yes	94	
Under 5%	52	27	51	20	68	6	76	44	12	57			36
6 to 10%	21	19	18	16	16	12	12	33	16	24			17
11 to 20%	10	15	13	17	9	12	8	3	28	10			15
21 to 30%	7	4	7	20	3	25	4	5	21	5			13
Over 30%	10	35	11	27	3	45	0	15	24	5			19
Location of Agency											Yes	93	
Rural	32	20	46	60	65	54	62	47	20	50			49
Urban	42	60	26	20	22	33	30	25	27	15			29

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Location of Agency (cont'd)													
Suburban	20	16	23	12	7	4	0	22	22	25			14
Reservation	0	0	0	0	0	0	0	3	0	0			0
Other	7	4	5	8	6	8	8	3	12	10			8
Number of paid staff											No	93	
Zero	3	0	1	0	1	0	0	2	5	0			1
1 to 10	30	12	23	28	32	30	40	27	34	43			30
11 to 20	32	50	40	47	40	44	31	29	35	33			41
Over 20	36	39	37	25	27	27	29	22	26	24			28
Number of minority paid staff											Yes	90	
Zero	48	28	45	23	54	16	58	48	24	50			36
1 to 10	31	40	34	56	37	61	36	40	43	40			44
11 to 20	21	28	11	18	4	11	4	13	30	5			15
Over 20	0	4	11	3	4	11	2	0	4	5			5
Have in-service training for staff on culture of minority groups	19	30	28	48	25	43	19	37	52	44	Yes	85	37
If no in-service training reasons are											Yes	52	
No minority in service area	38	18	32	6	47	4	33	32	5	36			24
Not necessary--all minority staff	0	0	2	1	0	0	0	0	5	0			1
Cost of program not in budget	14	35	18	41	15	36	18	23	28	27			26
Other	48	47	48	52	38	60	49	46	63	36			49

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Methods used to recruit paid staff													
Word of mouth													
White	35	38	33	37	34	21	29	29	32	18	No	83	32
Minority	31	33	32	33	27	19	21	29	29	12	No	82	29
Other agencies													
White	24	25	23	26	10	21	26	42	32	12	Yes	83	24
Minority	24	25	18	23	8	21	21	39	30	12	Yes	82	21
Professional journals													
White	21	4	11	14	12	5	21	19	11	0	No	83	13
Minority	14	4	7	13	9	5	21	19	9	0	No	82	11
Civil service													
White	21	8	26	24	19	33	7	25	30	53	Yes	83	24
Minority	21	8	28	24	17	33	7	23	28	35	Yes	82	23
Newspaper, radio, TV													
White	69	67	52	38	62	35	52	68	35	59	Yes	83	48
Minority	62	75	46	37	53	33	50	61	31	59	Yes	82	45
Employment agency													
White	10	33	19	29	29	21	50	29	16	6	Yes	83	25
Minority	10	25	21	27	24	19	43	29	16	6	Yes	82	23
Agency staff recommendations													
White	14	21	26	30	17	14	14	16	26	12	No	83	22
Minority	10	21	27	27	12	14	10	16	23	6	Yes	82	20
Community persons or groups													
White	24	29	16	21	20	14	17	16	30	12	No	83	21
Minority	28	29	21	19	19	14	17	16	34	24	No	82	22

Variable/Value	I	II	III	IV	V	IV	VII	VIII	IX	X			
Proportion of clients served who have a developmental disability											Yes	85	
90 to 100%	40	83	33	44	50	51	63	38	49	43			49
11 to 89%	27	9	21	25	22	16	12	21	15	12			20
Under 11%	33	9	46	31	28	23	25	41	36	35			32
Age of largest group of DD clients served											Yes	88	
0 to 1 year	0	0	1	2	1	0	2	3	3	6			2
2 to 4 years	21	8	11	8	5	16	13	13	15	17			11
5 to 9 years	11	45	12	13	4	14	6	26	12	0			11
10 to 14 years	14	20	18	11	0	11	4	8	9	0			10
15 to 19 years	7	4	8	12	5	11	6	5	11	11			9
20 to 64 years	46	64	41	53	83	48	66	42	49	61			56
Over 65 years	0	0	10	1	1	0	2	3	1	6			2
Number of DD clientele											Yes	80	
Under 10	17	0	18	13	12	10	7	17	22	12			14
11 to 50	30	17	31	28	33	39	41	43	27	29			31
51 to 100	17	17	11	14	15	27	24	14	10	0			15
101 to 200	9	21	10	13	20	5	7	11	8	29			13
201 to 500	22	11	13	21	12	0	10	6	13	24			14
Over 500	4	30	17	11	8	20	12	9	21	6			14
Size of autistic clientele											Yes	70	
Zero	71	87	79	75	82	74	65	59	68	77			73
1 to 10	29	0	19	22	17	23	33	33	17	23			21
11 to 50	0	9	1	3	1	3	2	0	13	0			4
51 to 100	0	4	0	0	0	0	0	3	1	0			1
Over 100	0	0		0	0	0	0	0	1	0			0

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Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Size of epileptic clientele											No	69	
Zero	48	61	64	56	53	54	59	39	60	57			56
1 to 10	29	13	27	32	36	31	36	46	19	35			30
11 to 50	10	3	8	8	9	6	0	11	8	12			8
51 to 100	5	9	0	4	0	3	0	4	4	6			3
Over	10	13	2	1	1	6	5	0	8	0			3
Size of mentally retarded clientele											Yes	69	
Zero	14	14	12	10	4	17	18	4	29	24			14
1 to 10	24	5	31	19	18	17	13	39	22	18			21
11 to 50	29	14	29	26	36	34	43	36	18	18			29
51 to 100	14	18	6	11	20	9	13	11	7	12			11
Over 100	19	50	22	35	22	23	14	11	25	29			26
Size of multiple diagnosis clientele											No	69	
Zero	33	32	45	40	34	37	33	18	38	12			36
1 to 10	33	18	21	25	31	20	31	39	24	35			27
11 to 50	24	18	11	19	25	31	15	21	22	24			20
51 to 100	0	9	5	7	5	9	8	7	6	12			6
Over 100	10	23	11	9	5	3	13	14	11	18			10
Size of minority DD clientele											No	66	
Zero	36	4	38	11	44	11	42	23	21	21			25
1 to	32	44	33	26	31	31	39	45	35	43			33
11 to 50	22	13	18	30	18	33	13	32	23	29			23
51 to 100	0	4	5	15	1	14	0	0	6	7			7
Over 100	9	35	6	18	6	11	3	0	15	0			12

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Method of referral for largest number of minority clients											No	80	
Self referral	15	9	15	16	16	7	10	3	14	24			14
Family referral	4	5	10	6	10	16	18	16	6	6			9
Medical referral	22	5	11	9	6	12	5	9	10	0			9
Non-medical professional referral	0	0	10	6	2	0	8	9	8	6			6
Other agency referral	26	46	29	29	38	30	26	38	32	35			32
Case-finding and outreach	7	14	4	9	9	7	8	6	6	12			8
School referral	11	9	15	18	6	16	10	9	13	12			13
Court referral	0	0	0	2	12	0	0	3	0	0			1
Other	15	14	7	6	13	12	15	6	12	6			10
Method of referral for largest number of non-minority clients											No	84	
Self referral	17	4	23	17	18	9	13	9	15	29			16
Family referral	3	4	8	9	13	16	20	16	9	6			11
Medical referral	30	4	16	9	10	19	4	22	11	6			12
Non-medical professional referral	0	0	8	7	5	0	9	4	9	6			6
Other agency referral	30	48	22	27	33	21	26	28	30	30			28
Case-finding and outreach	3	13	1	7	5	7	11	3	6	12			6
School referral	7	9	15	17	4	16	11	9	11	6			12
Court referral	0	0	0	2	1	0	0	0	0	0			1
Other	10	17	7	5	10	12	7	6	10	6			8
Most frequently provided service for DD clients											Yes	96	
Identification	38	11	16	19	14	26	18	26	28	21			21
Direct Services	16	15	9	15	22	4	12	13	19	21			15
Treatment	9	7	14	8	5	14	4	11	7	11			9
Education	16	15	26	33	28	35	20	26	21	37			27
Residential services	13	15	15	6	12	12	4	8	7	5			9

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Most frequently provided service for DD clients (cont'd)													
Employment	6	33	8	8	13	2	24	11	5	0			10
Family/Program support	0	0	2	4	2	2	2	0	5	5			3
Outreach	0	0	0	0	1	0	4	0	0	0			0
Other	3	4	9	7	3	6	12	5	10	0			7
Number of clients living in own home											Yes	69	
Zero	29	26	30	9	20	22	21	11	14	13			18
1 to 10	19	4	14	11	11	5	11	26	29	13			14
11 to 50	19	9	20	32	35	31	42	33	23	40			30
51 to 100	10	17	8	14	13	22	8	15	11	7			12
Over 100	24	44	28	35	20	16	18	15	24	27			26
Number of minority clients living in own home											Yes	61	
Zero	60	33	65	21	67	32	71	36	38	36			45
1 to 10	20	33	19	25	22	24	20	40	36	46			26
Over 10	20	33	16	54	11	44	9	24	26	18			29
Number of clients living in institutions											Yes 69	69	
Zero	65	42	60	74	60	65	64	70	73	50			66
1 to 10	0	17	14	14	13	14	15	20	6	29			13
Over 10	35	42	25	12	28	22	21	10	21	21			21
Number of minority clients living in institutions											Yes	64	
Zero	65	55	81	80	86	81	90	82	84	82			81
1 to 10	30	18	11	12	9	6	0	4	7	9			11
Over 10	5	27	9	7	5	14	11	4	9	9			9

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Number of clients living in out of home community placement											Yes	69	
Zero	55	25	55	47	20	60	23	36	44	36			41
1 to 10	15	0	13	25	22	14	28	36	21	21			21
Over 10	30	75	33	28	58	27	49	29	35	43			39
Number of minority clients living in out of home community placement											No	63	
Zero	80	50	74	70	69	69	78	54	68	55			69
1 to 10	15	32	19	21	23	14	19	39	23	46			23
Over 10	5	18	7	10	8	17	3	8	9	0			9
Have outreach program	57	67	44	63	50	64	60	52	57	53	Yes	85	57
Purpose of outreach program											No	49	
Referral of clients for services	17	13	6	9	8	12	15	0	11	22			10
Locating potential clients	17	19	9	15	14	12	19	35	16	11			16
Distribution of information	6	0	18	6	0	4	0	0	13	0			6
Community education and prevention	6	0	12	3	8	4	11	6	5	0			5
All of the above	39	69	42	53	63	62	48	35	47	67			53
Other	17	0	12	14	6	8	7	24	7	0			10
Methods used to reach DD clients in outreach programs													
Health fairs													
White	17	30	24	8	12	7	12	14	19	29	Yes	51	14
Minority	17	24	21	8	10	7	16	15	17	29	Yes	50	14

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Methods used to reach DD clients in outreach programs (cont'd.)													
Leaflet distribution													
White	28	41	37	36	46	44	40	24	43	43	No	51	39
Minority	28	41	40	36	71	44	36	30	41	43	No	50	38
Parent groups													
White	33	53	34	31	19	33	20	14	24	29	No	51	28
Minority	22	53	37	30	18	30	32	32	26	14	No	50	27
Posters													
White	17	18	13	17	15	11	8	14	19	29	No	51	16
Minority	11	18	13	17	14	11	8	20	17	14	No	50	15
Home visits													
White	50	29	34	40	37	33	16	38	28	57	No	51	35
Minority	44	35	37	39	31	33	16	40	26	57	No	50	34
Visits to other agencies													
White	44	53	34	52	56	67	40	52	43	28	No	51	49
Minority	39	53	40	53	51	70	36	65	43	14	No	50	49
Circulating mobile units													
White	11	0	3	2	0	0	8	5	0	0	No	51	2
Minority	11	0	3	2	0	0	8	10	0	0	No	50	2
Radio, TV spots													
White	17	12	29	30	17	26	32	5	19	14	No	51	23
Minority	22	18	29	30	18	26	24	5	19	0	No	50	23
Community meetings													
White	11	47	37	36	33	48	20	19	35	29	No	51	33
Minority	17	59	37	34	26	48	20	25	31	14	No	50	32
Other													
White	11	18	13	10	21	22	8	10	10	43	No	51	14
Minority	11	18	16	10	22	22	8	10	9	29	No	50	14

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Reasons for not having an outreach program											No	36	
Not budgeted	0	43	6	26	21	59	9	19	26	50			22
Too costly	0	0	8	5	2	6	13	19	9	0			6
Not sufficiently staffed	31	0	17	16	11	0	9	19	17	13			14
Waiting list already too long	15	0	11	3	11	6	4	6	0	13			6
Not needed, community already aware of services	46	57	56	47	47	29	44	38	43	25			45
Area to be served is too large	8	0	0	2	4	0	17	0	3	0			3
Did not think about it	0	0	3	2	2	0	4	0	0	0			2
Do not know how to set it up	0	0	0	0	2	0	0	0	3	0			1
Minority populations know about and use services to fullest extent possible	64	78	75	81	78	73	78	63	63	65	No	81	74
Factors preventing minority populations from knowing about and using services													
Language barrier	64	40	16	0	14	17	0	31	34	33	Yes	24	21
Lack of transportation	46	60	21	37	19	58	8	56	40	17	Yes	24	36
Lack of information about agency	64	40	63	66	67	58	77	69	57	33	No	24	63
Families too involved in "survival issues"	18	60	42	51	33	58	23	44	54	67	No	24	45
Lack of communication between staff and parents	18	0	5	3	10	0	8	25	0	17	Yes	24	8
Agency hours do not meet clients' needs	9	20	0	6	0	0	0	6	0	17	No	24	8
Cannot afford to pay agency fees	18	0	0	6	0	0	15	0	14	0	No	24	6
Other	27	0	32	31	38	17	39	13	37	67	No	24	31

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Eligibility requirements													
Income	3	14	17	30	14	14	15	30	17	30	Yes	83	20
Type of disability	45	61	47	51	55	66	45	58	51	59	No	84	52
Geographic location	52	57	41	35	51	31	28	24	36	35	Yew	84	39
Age	32	61	50	38	33	48	43	33	41	53	No	84	41
Sex	0	9	7	6	2	9	4	3	1	6	No	84	4
Marital status	3	0	4	4	2	5	4	6	2	6	No	84	3
Ethnic group	0	0	0	0	1	0	0	0	1	6	No	84	1
All of the above	0	0	0	1	2	0	2	6	1	6	No	84	2
No requirements	26	22	21	22	22	21	38	27	22	18	No	84	23
Time typically spent by client on waiting list											Yes	81	
No waiting list	67	36	55	63	71	62	61	68	74	69			63
1 to 2 months	20	55	27	24	14	23	14	21	15	31			22
Over 2 months	13	9	16	13	15	25	24	12	11	0			15
Round trip distance typically travelled by client											Yes	76	
Less than 10 miles	50	61	47	31	40	20	46	49	59	43			42
11 to 30 miles	23	28	44	54	41	43	34	27	34	43			41
Over 30 miles	27	11	9	15	19	38	21	24	8	14			17
Language other than English needed	55	48	26	19	29	40	25	59	65	50	Yes	85	36
Languages needed													
Sign Language	44	58	50	67	61	47	62	48	43	42	No	34	52
Spanish	52	57	50	36	36	65	62	67	87	58	Yes	34	60
Japanese	0	8	8	0	0	0	0	0	20	0	Yes	34	4
Chinese	0	17	13	0	0	6	0	0	38	0	Yes	34	7
Other	35	25	33	15	21	24	0	38	21	25	No	34	26

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Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Languages other than English spoken by staff													
None, English only	36	52	60	75	48	50	65	32	16	28	Yes	84	52
Spanish	45	44	28	19	31	32	23	50	75	56	Yes	84	36
Japanese	3	9	3	2	3	0	2	3	19	0	Yes	84	5
Chinese	7	4	5	1	2	2	0	0	32	7	Yes	84	7
Other	55	39	19	21	28	27	15	35	37	29	Yes	84	28
Materials about agency are printed in language other than English	29	35	31	18	24	28	21	35	61	44	Yes	86	31
Language other than English used in material													
Spanish	32	89	96	87	96	73	100	92	93	86	Yes	29	85
Japanese	0	0	8	7	0	0	0	8	15	0	No	29	5
Chinese	0	0	4	0	0	7	0	0	31	0	No	28	4
Braille	0	11	8	33	9	7	9	0	7	0	No	28	10
Other	11	10	4	7	5	0	9	8	20	13	Yes	29	11
Have a policy or decision-making board	76	89	80	84	92	68	86	90	83	71	No	94	83
Number of persons on board											Yes	77	
1 to 5	9	12	13	14	17	3	9	33	14	7			14
6 to 10	27	8	18	29	34	20	35	15	17	40			25
11 to 20	32	36	39	29	39	50	37	46	45	47			38
Over 20	32	40	30	29	10	27	19	6	23	7			23
Number of DD persons on board											Yes	71	
Zero	86	83	85	85	86	80	91	94	71	92			79
1 to 5	14	8	12	13	12	12	5	3	24	8			12
Over 5	0	8	11	17	11	8	5	3	5	0			9

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Number of minority persons on board											No	71	
Zero	64	56	55	24	75	11	74	72	32	67			48
1 to 5	32	32	33	63	24	78	26	19	49	25			42
Over 5	5	12	13	13	1	11	0	7	19	8			10
Number on board elected by community											Yes	69	
Zero	91	96	79	90	89	96	76	77	84	91			87
1 to 5	5	0	2	3	10	0	5	23	1	0			5
Over 5	5	5	19	7	2	4	20	0	15	9			9
Number on board elected by board members											No	68	
Zero	68	77	68	62	66	42	61	70	62	46			64
1 to 50	0	5	2	10	8	8	2	10	7	9			7
Over 5	32	18	30	28	26	50	37	20	31	46			30
Number on board appointed by public official											Yes	68	
Zero	77	91	86	65	64	92	88	77	79	64			75
1 to 5	5	9	0	10	16	0	0	10	7	9			8
Over 5	18	0	14	25	20	8	12	13	14	27			18
Number on board elected by membership											Yes	68	
Zero	82	32	75	81	75	77	76	76	70	91			75
1 to 5	0	0	2	4	4	4	2	3	4	0			3
Over 5	18	68	23	15	21	19	22	21	25	9			22

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Number of minority board members elected by community											No	70	
Zero	96	96	94	96	99	96	100	97	93	92			96
1 to 5	0	0	2	5	1	4	0	3	1	8			2
Over 5	5	4	5	0	0	0	0	0	5	0			2
Number of minority board members elected by board members											Yes	70	
Zero	86	91	85	74	93	58	88	94	76	85			82
1 to 5	14	9	13	23	6	39	13	6	16	8			15
Over 5	0	0	2	3	1	4	0	0	8	8			3
Number of minority board members appointed by public official											Yes	70	
Zero	96	96	95	77	95	92	98	97	87	85			89
1 to 5	5	4	5	20	5	8	3	3	9	15			10
Over 5	0	0	0	3	0	0	0	0	4	0			1
Number of minority board members elected by membership											No	69	
Zero	91	70	85	88	92	81	95	97	82	100			88
1 to 5	9	22	10	9	8	19	5	0	17	0			10
Over 5	0	9	5	4	0	0	0	3	1	0			2

Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Ways in which largest number of clients participate in implementation and delivery of agency programs and services											No	79	
Outreach activities	0	4	1	5	0	3	9	7	4	6			4
Serve on committees, etc.	17	13	13	15	16	8	11	7	16	24			14
Inform agency of their needs through their worker	40	52	33	42	52	28	22	55	37	35			40
Agency volunteer	0	0	9	3	4	0	2	0	0	0			3
Seek or contribute funds	0	4	0	1	2	3	2	0	1	0			1
Not involved	33	22	33	21	16	42	39	28	21	24			26
Other	10	4	11	14	9	17	15	3	21	12			13
Ways in which largest number of clients participate in planning of agency programs and services											Yes	80	
Serve on committee	13	0	16	9	14	3	15	9	16	6			12
Participate in parent-social worker meetings	17	13	14	19	9	17	17	16	17	18			14
Member of advocacy group	7	4	3	7	6	3	4	3	0	24			5
Suggestions made through case worker	33	39	19	25	43	31	17	41	24	24			29
Not involved	30	35	27	24	23	28	32	19	22	18			25
Other	0	9	21	17	7	19	15	13	20	12			15
Impact of board members on planning, etc.											No	75	
Great deal	83	73	71	75	76	64	76	58	76	57			73
Some	13	27	23	22	20	24	18	39	17	21			21
None	4	0	6	2	5	9	7	3	7	21			5

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Variable/Value	I	II	III	IV	V	VI	VII	VIII	IX	X			
Impact of direct service staff on planning, etc.											No	79	
Great deal	59	46	49	49	43	50	48	61	53	61			50
Some	37	50	48	49	57	47	50	36	42	39			48
None	4	5	3	1	0	0	0	0	5	0			2
Impact of administrative staff on planning, etc.											No	80	
Great deal	93	92	84	84	86	83	82	78	85	83			85
Some	4	8	16	14	13	11	18	18	15	17			14
None	4	0	0	2	1	3	0	3	0	0			1
Impact of volunteer staff on planning, etc.											No	67	
Great deal	4	5	8	8	7	6	8	4	16	0			8
Some	46	35	57	49	42	34	54	32	53	79			48
None	50	60	35	42	51	56	38	64	31	21			44

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